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ABSTRACT

This handbook offers guidelines to help parents prepare adolescent children with chronic illnesses or disabilities for independent management of their health care needs. In each chapter, guidelines for handling transition issues are presented in the context of the experiences and reactions of actual parents. Each chapter concludes with a summary list of helpful hints. Individual chapters address the following topics: preparing for independence in health care, letting go and changing roles, the impact of chronic illness or disability on adolescent development, sexuality, communicating with health professionals, self-advocacy in health care, paying for health care, and achieving independence. Extensive appendices include the following: a health care skills checklist; a health care checklist for residential settings; a self-evaluation questionnaire titled "Are You Ready To Manage Your Own Health Care?"; a personal transition health plan; a list of responsibilities of a health advocate; a list of resources on sexuality; a list of states with high-risk insurance pools; addresses and telephone numbers of the offices of State Insurance Commissioners; addresses of State Medicaid agencies; a list of state programs for children with special health needs; a list of resources for paying for health care; lists of other resources (e.g., Parent Training and Information Centers); and a bibliography of 21 references. (DB)

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Speak Up for Health

A Handbook for Parents

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Speak Up for Health

Preparing Adolescents with Chronic Illness
or Disabilities for Independence in Health Care

A Handbook for Parents

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Speak Up for Health

An Introduction

Teenagers with chronic illness or disabilities are faced with many challenges as they prepare for an independent life. The thought of living on their own raises many questions about the future. Will they go to college or vocational school, or find a job after high school? Where will they live and work? Who will they live with? Will they marry? How will they take care of their own health needs?

Michele, age 22, shares her thoughts on preparing for independence.

> I have had rheumatoid arthritis for more than 20 years, so I have become quite familiar with the health care system. When I lived at home, my mother always made my medical appointments. I'd just know the day that I had to go. When I went to the doctor, he always spoke to my mother. After I left home, my health care needs were not always met. It took me awhile before I realized that I was responsible for making doctor appointments, getting prescriptions filled, and coordinating my health care. *Now I speak to the doctor about my health issues.* I've gained experience, and now I have no qualms about standing up for the care I think I need. I've found

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that I have to be assertive. I firmly believe in advocating for your own health care.

My advice to adolescents with chronic illness or disabilities is to plan early for the transition to independent life. I had no idea how complicated the process would be. I had to actually be out in the community experiencing life to be aware of all the health concerns that would need my attention. Learning all you can about your illness or disability, knowing your rights, and communicating your needs to your doctor are important skills to learn in preparation for independence.

Living on my own has been a dream come true for me. I have been able to live the way I always wanted. I have my own apartment, and I have hired a live-in attendant to assist me through the day.

Health care issues are important. Knowing about your health and advocating for health care is important for a successful, independent life.

As parents, you are aware of the challenges your teenager with chronic illness or disabilities will face. Thoughts about the future raise questions about how to prepare your son or daughter for the challenges. After years of caring for your teenager, it can be difficult to let go and give up the responsiblity for his or her health care.

Speak Up for Health is a handbook for parents. It is written by parents and adults with chronic illness or disabilities, and it focuses on the importance of preparing for independence in health care. The authors share their experiences and insights that were gained as they struggled with transition issues. Each chapter is followed by a list of helpful hints that will assist you in guiding your teenager to become as independent as possible in managing his or her health care.

Preparing for Independence in Health Care

- Parents have been the primary caretakers of their children. The information you have is valuable, and your support is extremely important.
- Planning removes much of the fear parents and teenagers have about independence and provides knowledge that is vital for decision-making and risk taking.
- Maintaining good health while moving toward independence is essential for all areas of development.
- At age 18, in most states, adolescents are expected to make their own decisions about medical treatment.
- A health care advocate may need to be identified as a support for a person with a severe disability.

During the teen years, adolescents change daily. One minute they're in your arms wanting the security of childhood; the next minute they want the privileges of adulthood. Children at age 3 often inform their parents, "I can do it myself." At age 13, the phrase becomes, "I can take care of myself."

Parents of young adults with disabilities or chronic illness experience conflict with the notion of transferring control. They understand that independence is natural and healthy, yet they fear the high-risk consequences. The fear of letting a teen be in charge of his

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or her medication, or deciding about a medical procedure that may have life or death consequences, is difficult.

At age 18, in most states, adolescents reach the age of majority and are expected to make decisions about their own medical care.

However, in most states, adolescents will reach the age of majority at 18 and are expected to make decisions and sign release forms for medical treatment. This often comes as a shock to both parents and teenagers. Adolescents are confronted with the reality that they are responsible for decisions for which they may have little information. Parents discover that, by law, their son or daughter cannot be dependent forever. This does not include individuals whose disability requires that someone have legal guardianship for such purposes. One mother shares her perspective:

> Christian is 19 years old. He has epilepsy and mental retardation. None of the tests have shown why he has four to five hours of continuous seizures once a week. When he started high school, Christian wanted to be in charge of his own medication. He started talking about brain surgery so he could drive a car. I knew he was at greater risk of a seizure if he forgot to take his medication. I knew he could fall and seriously injure himself or die. I also know teenagers with a seizure disorder feel very little control over their lives. Giving him responsibility for his own medication meant some sense of control for him. Despite lots of worry, I turned that responsibility over to him. Brain surgery is a different story . . . for now.

Parents know more about the whole child: the quirks and habits, reactions and withdrawals, the facial expressions that mean fear or

wonder, and the eyes that say yes or no. Medical personnel are instructed to look for outcomes, test results, vital signs and specific medical reactions. They may not consider the teenager's emotional and psychological needs, as one mother learned.

> After five hours of repeated attempts to give my daughter a sedative for a CAT scan procedure, I saw a fear in her that I'd never seen before. Even though they had given her enough medication to sedate a 200-pound man, her anxiousness prevented the medicine from having an effect. I worried that if I allowed her anxiety to continue, I would destroy a part of her spirit that was so important to her whole-health person. I refused to give permission for the treatment.
>
> With 60 limp pounds in my arms, I checked out AMA (against medical advice). My daughter's pediatric neurologist approached us at the exit. He agreed the CAT scan could wait for a less anxious moment. It was the first time I had defied a medical order. On the drive home that night, I said to myself, "no one will ever put her through that terror again. I will protect her." That became a major part of my identity. I was her protector.

How does a parent relinquish the role of protector? How can parents find the comfortable path for their child to move from "dependence through independence to interdependence?" (Blum, 1992) Who can be trusted to care about all the emotional and psychological needs that come with having a disability or chronic illness?

Starting early in the teen years, planning together can remove some of the fear and anxiety. Your sons and daughters want and need information about their disease or disability. Many times information is withheld from children and teenagers. Parents, doctors, educators,

and others think that the truth will be difficult psychologically and emotionally. This is not always true. Fourteen-year-old author Corey Svien, who lived with cancer for 12 years and had 16 surgeries, shared this advice with the medical world: "Always tell the truth, straight on. If you don't, patients will lose hope. It's an insult to the kid not to tell him what's going on. And never underestimate the patient." (Kelly, 1991)

"Always tell the truth, straight on. If you don't, patients will lose hope."

Planning together is more than sharing information. Parents may consider transferring some responsibility (scheduling doctor's appointments, refilling medications, etc.) to the child. Together, parents and teens should explore health care financing options. Because medical and insurance issues overlap employment and independent living, they need to be part of the transition planning. Adolescents are faced with a health care system that expects them to know what they want, where to find it, and how to express their needs. Parents can find the right balance for independence.

There will be differences in the degree of independence, depending on the teenager's temperament, relationship with the parent, family system style, and the level of the disability. Some adolescents, at age 11 or 12, may become determined to care for themselves and understand the consequences of their mistakes. Some may follow the status quo, leaving decisions to the parent.

Teens with a severe disability may need additional support in caring for themselves. Parents may want to consider helping their son or daughter assume some responsibility for his or her health. The adolescent who is unable to be completely independent in accomplishing health-related tasks may still be able to do part of a task. For example, some teens may not be able to state the names and

side effects of their medication. However, they can carry the information in their wallet. They can also carry information about allergies, insurance policy numbers, and other medical data.

Parents may feel that their son or daughter needs someone to serve as a health advocate: a sibling, a friend, or a legal guardian who is comfortable working with the medical profession. The advocate may monitor the health needs, take notes at doctor's appointments, or stay informed of the person's health history to give feedback and support. The health advocate may facilitate communication between the person with disabilities and health care providers. Many people without any disability or chronic illness prefer to bring a friend or advocate with them to the doctor. There is a certain amount of stress associated with even a simple physical.

Health advocate

A family member or friend who will interact with health care providers on behalf of the person with severe disabilities who may need assistance or be unable to communicate clearly for himself or herself.

A number of skills and supports are required to manage one's own health care. The appendix contains a health skills list that will be helpful for planning with your teenager. It also includes a checklist for residential settings that will help evaluate the health care policies of a particular housing choice and an interview that can be used to learn how your son or daughter feels about taking charge of his or her own health.

Every individual should have the opportunity to live as independently as possible. Planning and preparation for both parents and adolescents are the key. Gaining more information and skills, while remaining a strong support for your teenagers, will ensure success.

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Helpful Hints

- Talk with your son or daughter about his or her health care. (See Appendix page A-1, Are You Ready to Manage Your Health Care?)
- Identify the health care skills that your son or daughter can perform and the skills he or she needs to learn. (See the Appendix for Health Care Skills Checklist.)
- Identify the people who can help plan for transition in health care, i.e, your physician, school nurse, family members. (See the Appendix for Personal Transition Health Plan.)
- Talk to your doctor about preparing for the future.
- Identify a health advocate, if needed. (See the Appendix for suggested responsibilities of a health advocate.)

Letting Go / Changing Rules

- "Letting go" is a necessary process experienced by both parent and child.
- Trial and error forms the cornerstone of the "letting-go" process.
- Taking time to examine personal feelings and to plan for the future are important steps in "letting go."

By Joyce Lindgren, Parent

I am a parent of several children with disabilities. They joined our family through birth and adoption. They are young adults now. Their transition to adulthood made one point very clear to me. Letting go is not a step – it's a process. Letting go must be acknowledged by both parent and child if it is to be successful.

As parents, we struggle with the many issues of letting go, including control, fear of failure, and fear of not being needed. Most parents want their young adults to become independent. As we begin to search for ways to let go, the journey is not always smooth. We

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may travel forward, backward and sideways, but slowly we arrive at the destination of living independently.

Independence and responsibility go hand-in-hand. Teens may want the independence, but not the responsibility. We may want them to be more independent, but we don't give them responsibility.

There are so many challenges to letting go. Health care issues include choosing adult health care providers, financing, guardianship, advocacy, and coordination of care, to name a few.

Where do you start? Choose one goal your son or daughter feels is most important to his or her independence. Break it down into small steps so progress and success are more apparent. Before you begin, identify "safety nets."

Many of us have experienced the excitement of watching circus aerial performers balance on wires with no safety net. Few of us have watched them practice with safety nets. For adolescents who are preparing for life on their own, safety nets are the smaller steps taken to achieve independence and the supports that assist them in their journey to independence.

What's important is that we travel, however slowly, toward independence.

Knowing that safety nets are in place made it much easier for me to begin transferring responsibility to my children.

I'd like to share how my children and I have struggled in learning to let go. Both sides have made mistakes, and sometimes it's been frightening and confusing. Your family may have different stories to tell. What's important is that we travel, however slowly, toward independence.

My daughter Nicki is a bubbly, enthusiastic 18-year-old with a strong sense of self and an absolute certainty that she can manage all aspects of her life. Nicki's disabilities — legal blindness, sensory-neural hearing impairment, learning disabilities, and attention deficit disorder – should, in her opinion, not be considered. It's her belief that past errors in judgment have no relation to the present. After all, she is 18!

Communication and compromise are essential for a successful health care transition process.

Nicki attends a residential school for the blind. She decided in her sophomore year that she would choose her own physician, make her own appointments, and travel independently to the clinic. My daughter did not wish to continue with the school clinic's physician.

Communication and compromise are essential for a successful health care transition process. Nicki needed to assert her independence. I needed assurance that she would get good medical care. The school nurse needed to feel she still had some control since she is accountable for Nicki's health care while she's a student at the school. The physician needed assurance that as parents we would stay involved in her health care. The physician, the school nurse and I all needed safety nets to feel comfortable in giving Nicki this responsibility and independence.

One safety net met the needs of the physician and me. It also assured Nicki's success in assuming responsibility for her health care. My husband and I made a special trip to meet the physician and discuss our daughter's health care. We agreed to telephone if any of us had concerns. We also assured him we would drive down and accompany Nicki when he felt it was important.

The Individual Education Plan (IEP) became an important tool. We shared the value we placed on Nicki's learning responsibility for her health care with the IEP team. The IEP provided an opportunity for discussion and finally agreement for the transfer of responsibility. The school nurse was a team member, and Nicki's accountability was written into the plan. Nicki is required to make her appointments in the school clinic so the nurse is aware of potential problems. This provided the safety net for the school nurse.

Some of our children may need safety nets throughout their lives. Finding guardians, advocates or support persons may need to be a part of their transition plan. I have been concerned whether one of my children will pay his medical bills and health insurance premiums on time. I was delighted to learn that there are financial managers who will assist individuals with budgeting, balancing check books, and paying bills.

Some of our children may need safety nets throughout their lives.

My son Orlando, or O.J., as we call him, is one of the most personable young men I have ever known. He joined our family at the age of 4, and he's now 19. O.J. is triplegic. Both of his legs and one arm have been damaged by polio. His early malnutrition also left him legally blind and with severe learning disabilities. O.J. charms everyone who knows him. He's very sociable and has a special love for people. He also is fiercely independent.

O.J.'s learning disabilities sometimes make it difficult for him to transfer learning from one situation to another. His ability to judge situations correctly is impaired at times. In making health care decisions, it is important that health care providers take time to explain treatments to O.J. more than once and to monitor his understanding and follow-through.

O.J. is seen annually by a physician who is an expert on polio. He has prescribed water exercises to O.J. twice a week to keep his muscles in condition. With improper care, O.J. could become a permanent wheelchair user. Presently he uses long-leg braces and crutches.

Following graduation, O.J. told me he wished to discontinue his regular swim therapy. My concern centered around two areas. I recognized his need and right to make his own health care decisions. I also knew the problem he sometimes has in judging situations.

Communication and compromise helped again. I explained my concerns to him. He agreed to swim until we both meet with his doctor. I can then be sure that O.J., the physician and I clearly understand the choices and possible consequences in the same way. In telling the physician that I will no longer be involved in O.J.'s health care, I'm also placing more responsibility on the physician. From now on, he will be responsible for explaining very clearly any orders and possible consequences that may result from not following a prescribed medical regimen.

Our biggest responsibility for our children has finally come: to launch them into a world of independence.

O.J. will make his own choices about his health care, and I will have the opportunity to discuss the importance of follow-up with him. We have identified a plan, and the safety nets are in place.

Our biggest responsibility to our children has finally come: to launch them into the world of independence. We cannot deny them this experience. For children with disabilities, one of the best gifts we can give may be teaching them responsibility for health care — the ability to care for themselves so they can continue to live and experience a full, independent life.

Helpful Hints

- Begin early to think and plan for your adolescent's transition in health care.
- Begin to think and plan for YOUR future as your child becomes a young adult.
- Identify the people and community supports that can help you plan and support your teenager when he or she is living independently.
- Experience the joy of a new beginning – yours and theirs!

The Impact of Chronic Illness and Disability on Adolescent Development

- All adolescents travel the same road to adulthood.
- The challenges of adolescence are greater for teens with disabilities or chronic illness.
- It is important to treat adolescents as masters of their own future . . . they are anyway.

A young woman recalls, "Adults expected me to live like a medical textbook, but I was more concerned with living like a teenager." (Chesler, 1987)

Adolescence is filled with growth and change. Between the ages of 10 and 18, children experience many physical, emotional, psychological and social changes. Some are difficult, some are easy, but rarely are they uneventful. Puberty carries with it a strong need to belong to the group, yet feel distinguished; to conform to peer pressure, yet stand superior; to understand vulnerability, yet remain omnipotent. All the mixed feelings and thoughts, and the trial-and-error experiences, help create a healthy self-image. This chapter

underlines the importance of viewing teens from the vantage point of "normal development" before considering the differences imposed by the chronic illness or disability.

Early Adolescence, Ages 10 to 14

As early as 10 years old, children begin a time of re-evaluation and upheaval in their lives. Body changes are accompanied by new feelings and new social pressures. Adolescents may feel lost, frightened and misunderstood. This can lead to tension between teens and parents and between siblings and peers.

Adolescents may feel lost, frightened and misunderstood. This can lead to tension between teens and parents and between siblings and peers.

Teenagers need to work through these major questions: Who am I? How do I decide for myself? What do I think about that? The learning arena moves beyond the family. Peers become confidants and role models. Self confidence, self esteem and personal responsibility will greatly affect the adolescent's coping with these pressures and with problem solving.

Late Adolescence, Ages 15 to 18

Moving into adulthood, adolescents ask, "Where do I go from here?" They will base their answers on values, beliefs, goals and expectations formed in childhood and early adolescence. Their conclusions will come from concrete experiences, abstract thinking and interactions with friends and family. Depending on parenting style, family priorities and cultural and ethnic background, the answers will vary. Older teens often have greater experiences of feeling happy and sad, of having accomplished success and failure, and of being trusted or betrayed. They have begun to believe that they have control over their life and a vision of independence.

The Intensity of Adolescence

Other factors may also influence a young person's adjustment in adolescence, including the severity of the illness or disability, the outlook for the future, the effects of the illness or disability on everyday functioning, or the need for constant care. The teenager may worry about the visibility of the illness or disability to others, especially peers. Many times it is the invisible disability that has the greatest impact on self esteem and identity. Teenagers may deny or hide their disability or chronic illness and not share their concerns with anyone. They are less likely to think about needs and outcomes for the future. Adolescents may experience an isolated and painful view of the future if they avoid asking questions or if the answers are not satisfactory.

The Challenges of Adolescence

Throughout adolescence, teens constantly revise how they feel about the world. It is part of the process of developing their own belief system. Positive and negative feedback from experiences and people, combined with self esteem and sense of control, help revise adolescents' views. Their exposure and interaction with the world is extremely important during this period of growth. Participating in sports, arts, student council, dances, and other activities provides interaction and a chance to meet friends. It can provide a way to use strengths and excel in areas that may not have been evident in school evaluations. The experiences of 17-year-old Mac, who has cerebral palsy, mental retardation, and a hearing impairment, serve as an example. Mac's mother shares his story.

> It was apparent early on that Mac loved sports. At first he watched them on television, but soon he wanted to participate. He worked very hard to perfect his skills. He

We found that Mac's interest in sports was a great equalizer when he was with his peers.

learned to swim, play basketball, bike, skate and bowl. We found that Mac's interest in sports was a great equalizer when he was with his peers. They were naturally drawn to his enthusiasm and willingness to try. Mac's skill and interest in sports became such a strength for him, we sought more and more activities. Today Mac plays soccer and basketball, manages the high school baseball team and bowls in a local league. Through these activities he has improved on a skill, boosted his self esteem, made friends and learned to be part of a group. He has grown into a confident young man.

Relationships are important: from casual acquaintances to intimate loves, from family to friends. Relationships, formed from common interests, provide positive support for teens with chronic illness or disabilities as they face the challenges of adolescence. Teenagers cannot ask "Where do I go from here?" if they have not experienced places to go nor someone to share it with.

The Importance of Letting Go

There are a number of things parents and families can do to support their teens with chronic illness or disabilities during the growth and change process. An essential first step toward independence is an awareness and willingness on the part of parents to begin to let go of control. As young people begin to assume responsibility, they need support and the opportunity to make mistakes. They need to see themselves as capable. Always emphasize the ability. It is very important that young people with chronic illness or disabilities have the opportunity to be involved with new experiences throughout the

They need to see themselves as capable. Always emphasize the ability.

adolescent years so they can learn more about themselves and about the world around them.

A closer examination of adolescence as it is experienced by teens with and without chronic illness or disabilities may assist parents in supporting teenagers through the challenges of this turbulent, but always exciting, period. The tables that follow examine adolescent development and offer suggestions for parents on how they can assist their child with chronic illness or disabilities through the teen years.

Early Adolescence: Ages 10 to 14

	As experienced by ALL adolescents	Additional concerns for adolescents with chronic illness or disabilities
Physical changes	· Body changes are accompanied by new feelings and social pressures · "Am I normal?" · "Who am I in this body?"	· Puberty may come early or late, putting teens "out of synch" with friends · May need additional teaching materials and opportunities for peer interaction · Lack of information about illness/disability
	· Body image and sexual self concept are of major importance · Self conscious about body	· Lack of opportunity to explore and express curiosity about body parts · Can be an intense and painful time for teens who see themselves as different and not included because of peer discrimination/ rejection
Peer relationships	· Peers become very important to the developing adolescent	· Not having a close friend to share feelings can cause more dependence on adults and little chance to affirm self image · Peers afraid they'll catch illness/disability · Lack of consistent contact with peers can result in social isolation
	· Adolescents are focused on the present and the world around them	· The illness or disability can become the main focus of the teen's life, as opposed to the "big picture" · Frequent hospitalizations may interrupt social life
Independence issues	· Need for greater independence	· Often overprotected and sheltered · Lack of control over illness/disability and medical care · Parental and child fear of "letting go"
	· Question the values and beliefs of parents · Occasional defiance of parental authority	· Limited opportunities to take risks / rebel · Too often, questioning is seen as non-compliant and the behaviors are associated with the disability or illness instead of being healthy teen independent behaviors
Personal beliefs	· Constantly revising feelings/views about the world	· Present concerns are often overwhelming so that future concerns are not addressed · Don't know all the possibilities for the future. Afraid dreams such as marriage or world travel are unrealistic
	· Trying to attain separate identity from parents	· Prolonged dependence on parents/family · Discouragement felt because of disability/ illness limitations does not empower individuality

Suggestions for meeting the developmental and social needs of adolescents with chronic illness or disabilities
· Explain the physical changes that are taking place · Teach adolescents about their illness/disability, its causes, treatment and prognosis · Discuss their perception of what they can and cannot do to reach their goals for a healthy life · Constantly recognize and promote strengths through touch, listening to verbal and non-verbal communication, and encouraging them to explore and take a risk
· Discuss information about sexuality, including topics of childhood exploration, physical changes and sensations, masturbation, wet dreams, and others · Listen to concerns of teens, respect their positive and negative feelings; follow with discussion of why people aren't always kind and how to respond to ridicule · Provide both privacy and social opportunities to explore their natural sexuality
· Write goals and objectives on IEP about social opportunities, developing friendships · Start a social club for teens – a place to meet and typical activities to do (music, sports, talk, games, and more) · Request an inservice or experiential learning time for students without disabilities or illnesses to give them a comfort level about the disability and remove the stigma associated with differences
· Make a collage or mobile with your teen that answers the question, "Who am I?" (things they like to do, read, want to be, thoughts, interests, etc.) · Discuss dreams for the future; discuss the ones that seem impossible · Ask questions: How will people describe you in four years? Who will be important in your life in four years? How will you be different or what will you be doing in four years? What are two things you can do now to reach that dream? · Continue to provide an emotionally safe environment (there are no wrong questions)
· Offer choices for personal control in clothing, hair styles, activities, music, hobbies, and more · Encourage creative approaches to attaining goals · Emphasize abilities of the adolescent · Respect and promote personal privacy
· Encourage openness and innovation · Encourage adolescent to "speak up" on his/her own behalf · Encourage problem solving and support "letting go" on the part of the young person
· Be sure adolescent participates equally in family activities, decisions and problem solving · Promote opportunities at home and school for teen to feel successful (make a bulletin board to pin pictures/words of all successes) and listened to, supported and appreciated (at the next IEP meeting make sure every person on the team lists two strengths about your teen) · Respect decisions, even if they differ from parent's view · Share your beliefs and values based on culture and ethnic background
· Provide many opportunities for interaction with other teens, with and without disabilities / illness · Take the opportunity to share information with other people, promote acceptance and sensitivity to help make the world responsive to the needs of the teen; if you value them, they will learn to value themselves.

Late Adolescence: Ages 15 to 18

	As experienced by ALL adolescents	Additional concerns for adolescents with chronic illness or disabilities
Physical changes	· Continuing development occurs amid dealing with the pressures of school, work, dating, parental expectations · "Who am I in the world?"	· Atypical physical growth pattern · Decreased opportunities to compare self with peers due to lack of social opportunities
	· Preoccupation with personal appearance · "How am I the same as – or different than – others?"	· Awareness of being different · Feelings of embarrassment over physical differences and hidden differences · Lack of appropriate role models (ones who have similar disability and not too much older)
Peer relationships	· Becoming part of a peer group · Dealing with peer pressures	· Possible lack of friends and social opportunities due to peer rejection · Teasing from peers · Sense of isolation and loneliness
	· Importance of dating and relationships	· Fewer chances to gain experiences that result in social immaturity · Fewer same and opposite sex friends · Sexuality may not be addressed · Withdrawal from social interactions
Independence issues	· Desire for increased independence from parents and family · Want to be in charge of bodies and lives	· Dependence on others for care, transportation · Therapies can hinder personal autonomy · Societal attitudes encourage dependence and pity
	· Engage in experimentation, risk-taking, "testing" limits	· Fear of risk · Limited opportunities for risk-taking · Freedom to experiment is often denied
Personal beliefs	· Begin to consolidate beliefs in the move toward adulthood · "Where do I go from here?"	· Options may be reduced due to limitations related to illness/disability, or attitudes and opportunities in the community · Frequently there is no one to "go with;" no one likes to reach out alone
	· Planning the future in the areas of education, career, marriage	· Future planning issues must be discussed in relation to illness/disability · Reliance on family and lack of support from community can make future planning difficult

Suggestions for meeting the developmental and social needs of adolescents with chronic illness or disabilities
· View love, caring and intimacy as part of teenagers' needs as human beings (parents often want their children to be loved, but not touched) · Plan activities such as sleepovers, camp experiences with peers · Experience is worth 10,000 words; plan activities that use strengths · Share ideas; write lists; cut pictures for a poster that addresses nutrition, exercise, cleanliness, etc., promoting independent health care
· Find role model either through school, Center for Independent Living (see Appendix), disability organization, or community center · Give information that clearly defines strengths and limitations of the disability or chronic illness; be open, honest, direct in answering teen's questions about body changes and sexuality · Acknowledge embarrassment, disappointment or anger about the differences
· Encourage community-based activities, i.e., work, church, synagogue leisure options · Promote increased control over choice of friends, where to go, how to get there, what to wear
· Give increasing amounts of control back to the developing adolescent · Allow and encourage choice in order to foster confidence and competence · Explore sexuality issues in relation to illness/disability, i.e., how sexual development/ functioning may be affected
· Promote self-esteem through listening, providing ways to get out and meet friends · Recognize rights, delegate responsibilities and acknowledge personal relationships in family, with consideration for cultural and ethnic values
· Be supportive in allowing adolescent to "learn from experience" · Allow degrees of experimentation · Allow adolescents to experience the consequences of their actions; mistakes are learning tools · Give parental advice carefully
· Help teens develop coping mechanisms, i.e., self-talk, "I can do it" · Teach them being angry isn't all bad (there are some things that they should be angry about) · Encourage teens to become involved with self-advocacy organizations
· Provide awareness and acknowledgement of those limitations related to the disability / chronic illness; what are the supports needed to gain as much independence as possible · Promote a strong sense of self-worth and the confidence to believe in one's potential and one's right to participate fully in the world around · Investigate job setting; talk to employers · Make appointment to look at apartments, group homes, and the personal essentials of furniture, pictures, etc., that give a sense of ownership and privacy · Talk about marriage and intimate relationships

Sexuality, a Part of Health

- Sexuality is an integral part of every person.
- Young people say they want more information from parents.
- Knowing the answers to sexual questions reduces vulnerability.

The important subject of sexuality is often ignored by parents and professionals. Many people are uncomfortable talking about sexuality and may see the teenager with chronic illness or disabilities as a non-sexual being. If the subject is addressed in the home or school, emphasis may be placed on fears surrounding vulnerability, disease, pregnancy and inappropriate behaviors. The human need for touching and loving is often buried in society's discomfort with sex. Instead of being part of a loving relationship, sexuality becomes a separate entity.

Sexuality is directly related to physical, psychological and emotional health. Parents can remove some of their teen's

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vulnerability by talking with him or her about sexuality and providing opportunities for social interaction. Given today's opportunities in education, employment, community living and recreation, young people with chronic illness and disability have many options and choices regarding their involvement in the larger community. Acknowledging and addressing sexuality is critical and essential for quality participation.

Acknowledging and addressing sexuality is critical and essential for quality participation.

Does my child have sexual feelings?

Yes. It is a myth that children and young people with chronic illness and disability are asexual. Every person is a sexual being, and sexuality is a positive part of life. Children are born with sexual interests, needs and feelings. Children with chronic illness or disabilities follow the same life cycle. Parents and professionals may avoid talking about sexuality. Societal attitudes may prevent experiences and opportunities that are similar to those teens without disabilities or illness. This does not take away feelings and thoughts. It can only add to the concerns. As one young man states with emotion:

> "I really want a girl friend, but it seems I always say the wrong thing or act the wrong way. Girls either laugh at me or feel sorry for me. It makes me feel invisible . . . and sad. I just want someone to notice me, hold me, love me, and think I am a man."

What is sexuality?

Probably the first thing that comes to mind when sexuality is mentioned is intercourse. Sexuality is much more. It is having friends, caring about others, being needed, being loved, and having opportunities to be with others. Having approval from others and being liked are some of the deepest human needs.

Sexuality is also holding hands, putting a head on a shoulder, hugging, touching or kissing.

Sexuality is also holding hands, putting a head on a shoulder, hugging, touching, or kissing. When parents and professionals concentrate on the risks and fears associated with sex and ignore the teen's need for touch, there are profound effects on body image, self identity and self esteem in the child.

Why me?

Parents are in the best position to teach sexuality to their children. They are the constant in their lives, and they know them best. You have natural opportunities to address sexuality in daily interaction with your child. He or she observes the caring that exists in your family. One parent shared her perspective:

> "My daughter's 13, and she's taking sex ed at school. She came home yesterday and started asking me questions. She'd seen a movie in class and hadn't really understood it – it went too fast, and she was too embarrassed to ask questions. We sat down and I explained in basic terms and showed her a few pictures from the encyclopedia. I never thought that having a learning disability was going to make it hard for her to learn about sexuality. And it also made me think of my own mother telling me about sex when I was a child. I wonder if my mother felt as awkward talking to me as I felt talking to my daughter. Probably." (NICHCY News Digest, 1992)

If you need further resources to introduce your child to his or her sexuality, don't be afraid to ask for help. Disability organizations, parenting groups, teachers, and doctors can provide resources and information.

Where do I start?

Relax, you already have. Tell your teens how you feel about intimacy, love, caring, and sexual relationships. Let them know your values about pre-marital sex, contraception, privacy and more. Young adults with chronic illness or disabilities want to make good choices about their relationships. Although they may disagree with parents, information and values are powerful decision-making tools. Parents may need to think through these issues first and know how they feel so that good communication can occur. (See the Appendix for bibliography of references on sexuality.)

What do I talk about?

This will depend on the age, experience, and temperament of your teen and the existing communication style of your family. Communication about sexuality should be open and genuine. Ask questions, share personal stories and create a comfortable atmosphere that says, "It's okay to ask anything."

Parents can explain their standards and values and the reasons behind them to their children during the early teen years. Give them complete and accurate information about body changes and the feelings that come with puberty. Share experiences about dating and how you feel about:

love	trust
premarital sex	masturbation
abortion	contraception
sterilization	same sex partner
virginity	abstinence
single lifetime partners	living together

Teens need to learn about parenthood, about sexual experimentation, about male and female contraception and about relationships. Parents need to talk about responsibility and about consequences, including sexually transmitted diseases (such as AIDS).

Above all, no matter how, parents need to SPEAK UP. Young people want straightforward information. They do not want judgments and lectures. They will be far more likely to accept parental standards if they understand and accept the basis for them. Young people, with and without disabilities or chronic illnesses, who know the answers to sexual questions are less vulnerable. They need practical skills and positive attitudes that will help them avoid exploitation.

Young people want straightforward information. They do not want judgments and lectures.

However, having accurate information, an understanding of the emotions and an interest and desire for intimate relationships does not do much good if there is no opportunity to meet and spend time with peers.

What is the social connection?

There is such a strong interconnection between self esteem and self identity, between body image and self acceptance, and between social development and sexual expression, that it is difficult to isolate one piece. Parents often hear the words "poor social skills" when talking to professionals about their child with a disability or chronic illness. IEP goals often focus on increasing social skills. Parents and teachers finally are realizing that young people can not be taught social skills from a textbook. Social skills are learned in a natural setting with people who care. If sexuality is about loving relationships, then the socialization that occurs in the lives of your

children is very important. During the early years, children need many opportunities to develop friendships. Often because of the chronic illness or disability, these opportunities don't "just happen." It is not easy to find age appropriate activities for teens, or to find other parents wanting to encourage social opportunities. Talking with other parents, learning about after-school activities, church, synagogue and community recreation are strategies some parents have found helpful in promoting their child's social life.

Social skills are learned in a natural setting with people who care.

How important is self esteem?

Parents want their children to feel good about themselves. Self esteem is often the drive that leads toward taking risks, developing friendships and a healthy sexuality. Self esteem comes from a positive self image fueled by individual success. Teens want to know they are important to others, that they are competent to handle the everyday realities of their lives, and that they have control over their behaviors and feelings. Again, this comes through exploring their environment and experiencing the bumps and bruises along the way.

Helpful hints

- Spend time evaluating how you feel about the issues of sexuality.
- Look for more information, both for parents and for teenagers. Go to the library or contact a disability organization to get this information. (See the bibliography in the Appendix for some references.)
- Repetition is important. Don't think because you talked about contraception or the emotional connection to sex once that it is embedded forever. Repeat, repeat, repeat.
- Teach your son or daughter the correct terms or language so he or she can express thoughts about sexuality clearly.

- Use the "teachable moments" that occur naturally in everyday situations. Be aware of your interaction, your touch, your respect for space and privacy, your caring tone of voice, and your willingness to let go.
- If this is all very uncomfortable for you as a parent, don't ignore the need for your son or daughter to learn about sexuality. Seek out a person or resource that your son or daughter and yourself are comfortable with and who has similar values to assist you in discussing sexuality.

Communicating with Health Professionals

- Communication includes body language, facial expression, signing, speaking out loud, and using augmentative devices.
- Communicating with health professionals includes listening, adding new information to your current knowledge base and values, checking emotional reactions, and deciding how to respond.
- Communication is the way needs are met. Interaction with the world can be done passively, aggressively or assertively.
- How you communicate is a direct reflection of how you feel about yourself.

Communicating with health professionals is essential to achieve good health care. Children need effective spokespersons and advocates when they're young. As they listen and observe, they learn. As teenagers assume the role of "expert" in their own health care, they will want the opportunity to speak up for their own health. One young woman shares her story:

> "I think you really have to speak up. There's one girl here that when you ask, 'How are you doing, Lisa?,' her mom will say, 'Oh, she's doing pretty good today.' I don't see how you can get through to the doctors.

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"I've had diabetes since I was 2, and I've learned . . . the questions to ask, and what you want to get done. As soon as I learned how to get my own shots, my mother let me go into the nurses alone, and so she'd build up my confidence that I could do things myself. So I felt better about going with her and kind of doing my own thing. She'd just ask questions, and if she didn't like the answers the doctors gave, she'd ask another question. And she'd always make sure I understood before we went on to the next point. And I just picked up those kinds of things from her. The last couple of visits I've been coming by myself. I look like I know what I'm doing and so the nurses just hand me papers and say, 'You know where to go, right?' And I say, 'Right!'" (Chesler, 1987)

Some children with chronic illness or disabilities have not been encouraged or allowed to speak for themselves. Some teens with chronic illness and disability have limited verbal communication skills. Still other parents feel it is easier and more efficient to speak for their adolescent.

It is important for parents to communicate clearly and assertively so that their children have a good role model. It is equally important for parents to encourage communication between teens and medical personnel. By having the opportunity to communicate openly, genuinely and assertively, adolescents learn good communication skills.

There are ways to improve communication. Here are some ideas to practice in conversation with your son or daughter.

Listening

An essential part of communication is listening. Although this may seem natural, each person listens from his or her perspective and often hears and stores only small pieces of information. If the topic is

emotional, listening can become distorted in order to deal with one's own emotions. Also, thinking about what to say next causes the listener to lose attention to what is being said. Using some simple techniques can eliminate these blocks.

Paraphrasing

Repeat the information you hear in your own words. Use phrases such as, "I understand you to mean . . . ," or "What I think you're saying is . . . ." Common understanding not only helps with immediate listening and communication, it also gives direction for future action.

Perception checks

Emotions are often part of communication. Having feelings acknowledged and validated allows communication to move to issues. If emotions appear to dominate a conversation, talk about them. If you sense that the person you are communicating with is giving a negative message through eye contact, facial expression or body language, stop and ask. Always speak from your feelings and without judgment. Use phrases such as, "It seems to me that you're frustrated," or "I sense from your frowns that I'm not being clear or I'm confusing you."

This allows everyone to express emotions, clear the "table," and communicate effectively.

These tools can be practiced by the whole family. Soon they become part of the natural communication, and your teenager with chronic illness or disability will learn to use them.

Ask questions

Health care professionals use professional terminology. It can sound like a foreign language. Teens can feel intimidated and too embarrassed to ask questions. Tell them it's fine to say, "I don't

understand," or "What does that mean?" Remind them that they have a right and responsibility to understand the information.

The ability to communicate well goes hand in hand with self image. When a chronic illness or disability has left a teen with low self-image, due to teasing or lack of opportunity to succeed, it is difficult to project oneself with confidence. It is important to work on being assertive. Again, practice in naturally occurring circumstances with your teen. Consider the three ways to communicate:

- Assertive: express thoughts and feelings, directly and honestly.
- Aggressive: not respectful of others, pushy, angry.
- Passive: allows others to make decisions.

Feeling successful, appreciated, responsible and cared for allows your son or daughter to communicate assertively. Encourage and support them when they communicate directly and honestly.

Helpful hints

- Talk with your teenager about what to expect in health care. Talk about what to expect from the doctor. Help your teenager communicate his or her needs. Help him or her find a primary care physician to coordinate health services.
- If your teen chooses to find a new physician, encourage him or her to make an appointment or talk to the doctor by telephone to do a mini interview. This way they can make sure they are a good match.
- It is a good idea to start a folder with medical information. Usually parents keep some records of medications, test results, doctors' names and other information. Transfer the information to your teen. If your teenager is non-verbal or has a communication disorder, assist them to express needs using alternative methods, i.e., communication board, facilitative communication.

- Before the doctor's appointment:

- have your son or daughter make sure the building is accessible, request an interpreter, or convey his or her specific need.
- Encourage your son or daughter to write down questions and issues ahead of time to make sure nothing is forgotten.
- Always talk about how much time may be needed with the doctor. Arrange for extra appointment time if needed.

- During the doctor's appointment:

- encourage information to be written down by your teen, an advocate or the physician.
- ASK QUESTIONS IF NECESSARY.
- Make time for your son or daughter to talk about jobs, school or social time so that the doctor receives a picture of the whole person. Learning about a teenager's life beyond the clinic wall is a wonderful perspective for doctors to hear. It may be the motivator that brings physicians more into the whole life planning process or even an IEP meeting.
- Choice is a major piece of empowerment and of high self esteem. Let your teenager know his or her right to refuse treatment if it is believed to be unnecessary or repetitive, have a high risk or serious side effects.
- Consider allowing privacy for your teen to ask questions regarding love, marriage, sex, contraception and more.

- After the appointment:

- Listen to how your son or daughter feels about new medication or other information. Let the teen do some problem solving and decision making for his or her health.
- Successful independence in health care insists on a partnership between parent, teen and physicians. The new partner is your son or daughter. Talk about shared goals, listen to questions and answers, respect individual choice, and understand everyone has a role in this partnership, but no one owns the body except the individual.

Self Advocacy in Health Care

- Self advocacy is what Speak Up for Health is about: the willingness, determination, knowledge, and power adolescents must have to communicate their needs, desires and feelings about their health care.
- Self advocacy requires a clear self concept based on an individual's beliefs, values and goals.
- Self advocacy is influenced by past experience, parental values, cultural traditions, media, personal strengths, preferences and interests.

Self advocacy is a process, not an event. Children begin to learn about self advocacy by watching their parents be good advocates.

Your child has watched you communicate with physicians and therapists who have been involved with his or her care. No doubt you have learned a great deal about the particular illness or disability. This knowledge of the disability and your rights form the foundation for good advocacy.

Self advocacy takes time to develop. However, this is time well spent. Your teen will have the skills to get needs met and to pursue dreams.

Most teens agree that without self-advocacy skills, they cannot successfully plan for independence. LeAnne, a woman with cerebral palsy, describes her first attempts with advocating for her health care needs.

> It was scary for me to start making my own doctor appointments. I feared that the receptionist wouldn't understand my speech, which is affected by cerebral palsy. Previously, my mother had done all the calling. Mom told me that I would have to be prepared to answer questions and that it would be wise to have my insurance card in front of me. At that time, I was still under my parents' coverage.
>
> I remember making my first appointment. I felt out of breath, but the woman seemed very patient as she waited for me to tell her what I wanted. She asked the usual questions about health insurance, and I answered.
>
> After I hung up the phone, I had a sense of achieving a small victory. Little did I know that in the next year I would have to learn to trust my own instincts in choosing the right doctor.
>
> When my shoulders and legs started aching, I began to wonder if there was something wrong besides fatigue and tenderness due to cerebral palsy. I made an appointment with our family doctor.
>
> After reading X-rays, the doctor said, "You have arthritis. And although you may be a little young, it's not unusual for people with cerebral palsy because of the wear and tear on your muscles."
>
> He advised me to rest more and take an over-the-counter medicine.

As the months went by, the pain and fatigue persisted. I finally made an appointment with a specialist. After several tests, she identified a condition that indicated I needed surgery.

I was really confused by the different information, and when it came time to make a decision, I elected not to have surgery. I felt I did not have enough information. Despite the pressure of the physicians, I decided to wait.

After some thought, I decided to get a second opinion. I called the local hospital and described what I wanted:

"I am a 20-year-old woman with cerebral palsy. I'm having stomach pains. I need to see a doctor who will listen to me and believe me."

That day, I met the doctor who became my family physician. He discussed each of my concerns and offered detailed information regarding my condition. I began to believe and trust him. That made all the difference in the world. Eventually, I was able to make an informed decision about surgery.

I asked my mother to come with me to see the surgeon. I know how nervous I get when I see a doctor, which causes me to sometimes miss important information. This way, both of us heard the same things and compared notes afterward. It helped to reinforce my decision to go ahead with the surgery. I think it's helpful to have someone with you to support and reaffirm what you are hearing. I continue to bring a close friend to important appointments.

That was my first experience in the hospital, let alone surgery. While I was apprehensive, I had confidence in my doctors. The surgery was successful, and I felt very relieved to have it behind me.

If I hadn't kept searching for a doctor that I could believe and trust, I don't know what would have happened. Trusting my own instinct, having family support, and belief and trust between doctor and patient are key ingredients to self advocacy in health care.

Trusting my own instinct, having family support, and belief and trust between doctor and patient are key ingredients to self advocacy in health care.

Knowledge is important. Trust and support are key. Still, sometimes it is difficult to hand over the responsibility of health care to your son or daughter. It seems that there are so many risks. What if he forgets his medicine? Did he remember to call the doctor? Will she ask all the questions she needs to ask? Will he make the right decisions? However, as one foster father explains, the need to make medical decisions is each person's right and is necessary for independence.

Kelly was in an institution for the first few years of his life. He came to live with me when he was 14.

He used an electronic device to communicate. We had to fight very hard to get it funded because people thought he was too disabled to communicate. Despite his severe disabilities, he had to make very serious decisions about his health.

After he moved into a group home in 1983, he decided to have a gastrostomy. I couldn't imagine why. I had his power of attorney for emergency medical procedures. At a meeting to discuss the possibility of surgery, I asked, "Kelly, why would you want to do that? You can't interact as much with people, you won't taste the food, it makes you more medically fragile, it makes your living more restrictive."

He said, "The reason I want to do it is because I'm afraid of choking. There are all different kinds of people who feed me. Some do very well and some don't do well, and I don't like that."

A surgeon, a social worker, his father and other team members were present. Kelly made the decision. He knew about his disability, he knew what he wanted, and he knew what was right for him.

I'm still in contact with him, and when he had an opportunity to move back to his home in Maui, he chose to stay on Oahu to maintain his independence.

Information and support are important, but without choice based on personal values and priorities, there is no self advocacy. Being valued is critical for self advocacy.

Helpful Hints

- Ask your teen about his or her concerns and thoughts.
- Think about your teenager's strengths.
- Be aware of the how the system discourages your teen's independence. Persons with disabilities or chronic illness are seen as helpless and in need of charity. Society's goal is to

create a normal person instead of a normal experience. The system says there is not enough time to focus on self advocacy. Assertive behaviors often are seen as non-compliant behaviors.

- Ask yourself how often you give choices to your son or daughter about health care and other areas.
- When a family trip or activity is planned, does it focus on the illness or disability?

▩ Set goals that bring about changes.

- List the telephone numbers of doctors and other health care professionals in a book for your teenager.
- Help your teen identify health skills that he or she will be responsible for.
- Encourage high school social activities for your teen, such as after-school clubs, dances, etc.
- Have your teen attend the IEP meeting, choose goals and write objectives.

▩ Knowledge is power.

- Take your adolescent to the library and find information about the illness or disability. It may promote questions and discussion.
- Find a self-advocacy group or support agency that will have information plus psychological support.
- Have your teen share information about the illness or disability with teachers, doctors, employees, friends.
- Teach your adolescent to be aware of his or her rights and to exercise those rights.
- Talk about the value of belonging, and feeling competent and worthwhile.

▩ Identify responsibilities for your teenager, and encourage participation. Have him or her:

- Prepare meals.
- Take care of the yard.
- Do laundry.
- Start a savings/checking account.
- Care for younger siblings.
- Care for the family pet.
- Listen and be a good friend.
- Learn to be on time.
- Use free time to begin hobbies or activities of interest.
- Order medication from the pharmacy.

Practice increases skill and confidence. Self advocacy is not a specific skill. It is an accumulation of internal and external experiences that lead to confidence.

Paying for Health Care

- If your teenager turns 18, completes high school and does not go on for further schooling, he or she may no longer be eligible for the family's insurance.
- Exploration of health care financing options should begin by the time your son or daughter is 17 years old.

The challenge of obtaining medical health insurance, either private coverage or public in the form of medical assistance, is a major concern for persons with chronic illness or disabilities. However, there are options for your son or daughter. Exploring these options should begin by age 17 or sooner – many adolescents may lose their family's coverage by age 18. In insurance terms, this is known as the age of independence. A son or daughter who turns 18, graduates from school and does not go on for further education may no longer be eligible for the family's insurance. The FIRST STEP is to find out at what age your son or daughter may lose coverage on the family health insurance. Do this by reading your insurance policy or calling a claims representative at your insurance company.

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Here are some options available for your son and daughter as they turn 18. Please keep in mind that the goal is to obtain insurance coverage. This does not mean that the insurance fees will always be reasonable. Persons with chronic illness or disabilities consistently pay higher costs for health insurance coverage.

Glossary of insurance-related terms

continuation
the ability to continue group coverage for a specified period of time when coverage would otherwise be terminated

preexisting condition
a health condition of an individual which existed before the individual became insured

premium
the monthly, quarterly, or annual charge one pays for insurance

prior authorization / prior approval
approval for insurance coverage for a specific service that assures reimbursement for the service

waiting period
length of time a person must wait from date of employment or application for insurance coverage before the insurance plan goes into effect

Private Plans

The following are options for people considering private health insurance.

OPTION 1:

If your son or daughter turns 18 and enrolls full-time in college or vocational school or remains in high school, he or she can continue on the family's health policy until age 22 or 23 (depending on the policy).

OPTION 2:

If your son or daughter does not continue in school, you have the opportunity to keep him or her on your insurance policy with the COBRA continuation policy. (COBRA stands for Consolidated Omnibus Reconciliation Act, a federal law for companies with more than 20 employees.)

You must notify your employer within 60 days of when your son or daughter turns 18. COBRA coverage is available for three years.

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Under COBRA, your teenager may continue on your family's group insurance plan by purchasing the company's group plan. One advantage of this option is obtaining insurance coverage which does not include preexisting condition exclusions. Any medical expenses that result from a chronic illness or disability will continue to be covered. Your young adult will be offered the same plan as was previously available. The full cost of the plan may be quite expensive; however, it will probably be less expensive than a comparable plan offered under nongroup rates.

For further information on COBRA, contact your insurance benefits specialist at your company or call the state insurance commissioner's office. (See appendix for list.)

OPTION 3:
Contact your state health insurance commissioner to see if there is a mandate that allows young adults to remain on the family policy if they are unable to obtain self-sustaining employment due to a physical or mental disability. More than 30 states have this mandate (McManus, 1989). Under the mandate, you must notify your employer within 31 days that your child has turned 18. You can then purchase continuation coverage through your employer. Your child may remain on this insurance as long as you carry the coverage. This law does not apply to employers who are self-insured.

OPTION 4:
If your son or daughter is attending college, even part-time, encourage him or her to explore student health insurance. These plans are usually inexpensive (about $250/year in 1988) (McManus, 1989). These plans are different than the standard student health services available on most campuses.

These plans usually have a preexisting condition clause or a waiting period, usually up to one year, before they will pay for treatment of a preexisting condition. However, they cover other

health needs during the waiting period and provide coverage for the preexisting condition after the waiting period.

These plans vary in their quality, but they are an option worth exploring.

OPTION 5:
Contact Blue Cross or a large health maintenance organization regarding their open enrollment period. Open enrollment may be offered continuously or periodically. This is a period in which anyone can enroll for insurance and will not be denied due to a preexisting condition. Open enrollment never denies coverage outright, but companies may limit coverage or treatment associated with a preexisting condition.

OPTION 6:
State high risk insurance pools are available in several states. (See the Appendix for list.) People are usually eligible if they can prove that they have been turned down by insurance companies or if the cost is prohibitive.

These high risk pools offer fairly good coverage, but they often carry a clause for a waiting period for preexisting conditions. Contact your state's insurance commissioner for further information. (See the Appendix for list of states.)

Public Plans

The following options are for persons using public insurance, often referred to as Medical Assistance or Medicaid.

OPTION 1:
If your family has public insurance in the form of Medical Assistance or Medicaid, your son or daughter will be excluded from your coverage when he or she turns 18, if he or she does not go on to further schooling. However, some states have an option for coverage

for adolescents to ages 19, 20 or 21. Contact your state Medicaid office for information. (See the Appendix for a list of state Medicaid offices.)

OPTION 2:
If your child goes on to college or vocational training, he or she will be excluded from coverage on your policy by age 19 unless you live in a state that covers adolescents to age 20 or 21. Contact your state Medicaid office for information. (See the Appendix for a list of state Medicaid offices.)

OPTION 3:
Many adolescents with chronic illness or disabilities who are eligible for Supplemental Security Income are eligible for medical assistance in some states. Contact your state Medicaid office to determine if you automatically receive medical assistance when you are eligible for Supplemental Security Income. (See the Appendix for a list of state Medicaid offices.)

Supplemental Security Income (SSI) is a federal program that provides monthly cash payments to persons who are disabled and have little or no personal income or resources. Prior to age 18, parental income is considered for eligibility. After age 18, only the individual's income is considered for eligibility. SSI can provide important income. To check on eligibility, contact the federal office at 1-800-772-1213.

OPTION 4:
If these options are not available to your son or daughter, exploration of local public health clinics and community agencies may be options for routine health care.

State Programs for Children with Special Health Needs

This is an option for families who have either a private or a public insurance plan. These programs often provide diagnostic services and

reimbursement for inpatient and outpatient treatment. Some may pay insurance premiums, deductibles and co-pays for eligible families. For further information and eligibility criteria, contact your state program. (See the Appendix for a list of state programs for children with special health needs.)

Appealing a Claim with Private Insurance

When you disagree with private insurance coverage of your claim, or your private insurance refuses to cover treatment or equipment, you have the right to file a grievance and appeal for coverage. Doing your homework, being prepared, and being persistent are the keys to getting what you need from your insurance company. There are several steps to follow that will help you get what you want.

1. Know the grievance procedure for your insurance company.
2. If coverage is denied, do your homework. Study your policy, the actual certificate, to understand the coverage you are entitled to.

   If you have difficulty understanding the policy, ask the claims representative at your insurance company to explain it to you. If you belong to a group policy through employment, it is also important to notify the personnel or benefits employee about your concerns. They are interested in their employees receiving the benefits they are entitled to and getting what they are paying for.

3. If you feel that the policy supports your position, call the claims representative at your insurance company and state your case. Be sure to get the representative's name. Keep accurate notes on each call, including the dates and time of each conversation and the names of the persons you spoke to. Keep copies of any letters.

Ask for an explanation of the company's action and where in the policy the action is substantiated. If you do not understand the explanation, state your position and reasons based on your interpretation of the policy. You are entitled to use the plain language of the certificate.

If there is an agreement during the conversation, do not hang up until you have a clear understanding of what the follow-up procedure will be to resolve your concern. Write a letter to the company stating your understanding of what will take place.

4. If you cannot resolve your claim, move up the levels of supervisors. Ask to speak with the claims supervisor or the manager. You may also wish to inquire about the company's claims review process and request a review. Ask about the membership of the committee and when it meets.

   In preparation for review, ask for help from your doctor or other health care providers to substantiate your claim. Some families have included scientific articles showing certain treatments that have helped children with a similar chronic illness or disability. All this information strengthens your case.

   Appealing your insurance claim will give you an opportunity for review by officials who have the authority to give you what you need.

5. You do not have to wait until your complaint has gone through the grievance procedure of your insurance company to get outside help. File a complaint with the office of the state insurance commissioner. Contact the insurance commissioner's office to learn how to file a complaint. (See the Appendix for a list of insurance commissioners' offices.)

The key to this process is consistency and good records. (Gaylord, 1988)

Appealing a Claim with Medicaid

If you do not agree with a decision made by Medicaid, you can appeal. You will be notified of a denial of services by letter. This denial letter will include instructions on how to appeal.

You must appeal within 30 days after notification of the denial. You can take up to 90 days if you have an adequate reason for not appealing within 30 days. (These are Minnesota guidelines. Your state may be different. Contact your state's Medicaid office for guidelines.)

A hearing will be set up in your area. At the hearing, you can explain why you believe denial of coverage was wrong. You may represent yourself, or ask a friend, an attorney, a relative, or somebody else to help you.

An appeals referee will hear and decide the case. You will receive the decision by mail, usually within a month of the hearing. If you are not satisfied with the decision, you have 30 days to appeal to the district court.

Helpful Hints

- Involve your son or daughter in discussions about health care financing.
- Learn what questions to ask as you explore insurance options. Here are some questions to consider:

- What are the specific needs of your son or daughter? Consider:
  Medication costs
  Home care
  Durable medical equipment (eg., wheelchair, glucose monitors)
  Preventive health care
  Physical, occupational, or speech therapy
  Long-term care

- Be sure the plan will meet your needs. If you have a specific need, ask the company directly about coverage. Check about limitations in cost and length of services.
- Are there lifetime limits? Does the insurance stop paying after a certain maximum limit is met?
- What disposable supplies are covered (e.g., catheters, syringes)?
- Read your entire insurance policy – not only the advertising brochure, but the legal document. Know your coverage and the procedure for grievance. This will facilitate the process for complaint if or when the time arises. Share the information with your son or daughter if possible.
- Find out the "age of independence" in your family policy.
- Advocating continually in health care, particularly in financing, is essential. Be aware of what is going on, in your state and on the federal level. BE ACTIVE in the process to gain adequate health care financing for all.

Achieving Independence: A Personal Story

by Nicole Roberts, young adult

Being a person with Muscular Dystrophy, I have faced many challenges in my life. The day I began to make decisions about my own medical care stands out as one of the biggest challenges.

Pneumonia is a common ailment for me. It usually begins as a simple head cold, and then slowly creeps its way into my lungs. When I was 15 years old, I experienced a very severe case of pneumonia. I woke one morning and felt very bad, and I was scared. My parents were at work. I was having more and more difficulty breathing. I felt like I was suffocating.

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I picked up the phone to call my mother at work. Before I dialed her, I thought to myself, "I can handle this." I decided that I needed to assert myself. I knew what was best for me; I knew I had to call an ambulance and get immediate treatment.

I felt utter and pure fear as I waited for the paramedics to arrive. I was afraid for my health; I was in worse shape than anyone, including myself, had been fully aware. I had never been in an ambulance before. I didn't know how they would treat me. Also, I had never faced the hospital scene alone. I was anxious about the entire crisis that I found myself in medically.

"I finally started trusting myself to know what was best for my life."

Equally as strong of an anxiety was my concern about what my parents would feel about my taking charge and calling an ambulance. This was the first time I had done anything this drastic without conferring with them. I had always believed that they knew what was best for me, and I had trusted them to take care of me. This time I knew I was right. I needed help right away, and I did not have time to call my parents.

This event marked the beginning of my journey toward independence. It was clear to everyone that I had made the right decision by calling an ambulance, and later I made the right decision again by insisting that I be hospitalized. From this I gained a new feeling of self assurance and self reliance. I finally started trusting myself to know what was best for my life.

As time progressed and high school graduation neared, I began to worry. I knew my life was about to take a radical turn. On one hand I was excited about it, but on the other hand I knew that now was the time for me to step forward and begin applying all that I had

learned in my life. I knew I would have to find a job, pay for school, and decide how I would spend my days, instead of having my life prescribed by a high school schedule. A few of my friends were already living on their own with full-time attendants in subsidized accessible apartments. I started putting my name on waiting lists at various apartment complexes. I interviewed for many jobs, but had a much harder time than I imagined finding an employer willing to adjust the workplace and the job to fit me. After a couple months, I found a good-paying job and was able to figure my finances in order to take some college classes. I was very busy, and I felt quite independent, with one exception – I still lived at home with my parents.

I received a few offers from accessible apartment buildings with vacancies, but I could never find an attendant to live with me in time to accept the apartment. Vacancies were rare, and each time I passed up an opportunity I would lose hope of ever being completely independent. My parents were supportive in the sense that they said I could live with them for as long as I wanted. I wondered if they believed I could live in the "real world." This upset me and made me even more determined to leave home.

"I felt quite independent, with one exception: I still lived at home with my parents."

Several years later, I was nearly ready to give up hope of ever being my own free person. I expressed this hopelessness to a metro bus driver who was taking me home from work one night. He listened to me carefully, and at the end of my moaning and groaning, he said, "Well, it's scary leaving the nest."

Suddenly I understood; I was afraid. I never thought I could be afraid to move out. I thought the only problem was that I was having

a terrible time getting everything in my life to correspond. It did not occur to me that I could be afraid of leaving home.

A week later, I woke up with a horrible stomach flu. My mother was forced to miss work and stay home to take care of me. As I watched her dial the phone and call in absent from work, I felt the security of knowing she would take care of me all day. I was so glad that I was living at home. I would be terribly scared to be sick and alone in the world. Who knows if my attendant would care enough to stay home with me all day? What if I got pneumonia and my mother wasn't around to give me a treatment? What if I wanted to go to bed and my mother wasn't around to put me in bed? Is there anyone else on Earth who can manage these essential things? Instantly, I found what had been preventing me from making a full-hearted effort to leave home: my intense fear of sickness, pneumonia, and everyday personal cares.

"I felt my life was moving ahead until I learned about health insurance."

These questions, once made conscious, could be dealt with. I figured out some plans that my attendant could enact in the event of an illness or pneumonia. I thought of ways to explain my daily personal cares to another person so that they could easily learn and respond to my needs. In addition, I realized that some of my fears were just plain ridiculous. After this, I grew more certain that I could teach and rely on another person to take care of me.

With my new revelation, I delved deeper into the world of public assistance for persons with disabilities. I found possible solutions to my problems, and discovered sources of help. I felt my life was moving ahead until I learned about health insurance. My father explained the bottom line to me: if I left home, I would lose my insurance coverage. I had to wait three months, after moving out, for my medical assistance to kick in. Meanwhile, I would have no

insurance. My family said they would not allow me to leave under these conditions as it would make them responsible for any bills I accumulated in those three months of waiting. It all seemed like another Catch-22. I had never known what insurance was all about, let alone that it was so essential. I studied, fought, asked questions, and filed appeals to our insurance plan until finally they agreed to cover me during the waiting period, even though I would be living separate from my parents.

"On my own I stumbled into many things, including love."

In the meantime, I had found a friend willing to live with me and be my attendant. Within a couple of months an apartment became available. I agreed to move in. With my new understanding of insurance, my job, my attendant, my promising academic career, my self assurance, and my old bedroom furniture, I entered my new life.

On my own I stumbled into many things, including love. I was 20, but no one had taught me about my body in terms of the possibility of conception or how to safely avoid conception. If I did become pregnant, I didn't know if I could carry a baby full term. If I could have a baby, I didn't know the likelihood of my baby having my disease. In fact, I didn't even know if I could have sexual intercourse. No one ever talked to me about sex.

Obviously, I had to deal with these issues. They were paramount on my mind. I didn't feel comfortable talking with my parents, since they had never brought the subject up with me, and I felt shy and nervous about approaching my doctor. He had been my doctor since I was 6 years old. We had established an open relationship, and he always listened to me when I told him about my health. Yet, I had never asked him about sexual issues, and I was almost angry that I had to now.

While I waited in his office alone, unusually nervous, I planned how to best ask him about sex and reproduction. I felt uncomfortable. I wished that earlier he would have told me himself. That way I could have the information I needed and I wouldn't be having to ask for it myself. I didn't want him to know that I was interested in this subject.

I couldn't help but wonder why everyone had overlooked the topic of sexuality with me. Perhaps they figured that since I was in a wheelchair I would never find a willing sexual partner. I had feared that could be my life scenario. I started to feel bad, and I had second thoughts about whether I was really worthy of pursuing a sexual relationship. Perhaps avoiding the issue was the polite way of telling me, "Sex is not for people with disabilities."

When my doctor entered the room, I was so tense I was hardly able to speak. He looked at me inquisitively and tried to start a conversation. I was having a difficult time simply chatting with him. I wished I had a female internist instead of a male pediatrician.

"This is my life. I am in control. I can choose."

Suddenly I remembered I was an adult. I stopped and thought, "If I want to have a sexual relationship, I don't have to feel embarrassed. And if I want new doctors to talk about it, I can get new doctors. This is my life, I am in control. I can choose." I was relieved. Now that I had an alternative, I felt more comfortable with my present doctor. I knew I didn't have to ask him all my questions. Feeling secure, I told him that I was very happy living on my own, but I did have some new concerns that I would rather discuss with a female doctor.

My doctor took out a pen and a piece of paper. He wrote down the name and phone number of a woman doctor for me. He smiled

and said, "I understand why you would be more comfortable with a woman doctor now."

Today I live in my own apartment. I have an attendant who provides me with the care I need to live independently. I make my own decisions about my health care, and I train the people who help with my health care treatments.

With freedom comes responsibility, and like everyone else, my life has its share of challenges. However, owning my life is worth any challenges I encounter along the way.

Appendix

Health Care Skills Checklist

Health Care Checklist for Residential Settings

Are You Ready to Manage Your Own Health Care?

Personal Transition Health Plan

Responsibilities of a Health Advocate

Sexuality, a Part of Health: Resources

States with High Risk Insurance Pools

Offices of State Insurance Commissioners

State Medicaid Agencies

State Programs for Children with Special Health Needs

Paying for Health Care: Resources

Other Resources

- National Resource Centers
- Parent Training and Information Centers

Bibliography

Health Care Skills Checklist

Skill	Performs independently	Performs parts independently	Needs practice	Plan to start	Skill accomplished	Comments
Describes chronic illness or disability						
Understands implications of chronic illness/disability on daily life						
Accesses medical records, diagnosis information, etc.						
Prepares and asks questions for doctors, nurses, therapists						
Knows medications and what they're for, or carries information in wallet						
Is responsible for taking own medication						
Is responsible for doing own treatments						
Gets a prescription filled/refilled						
Calls to schedule own medical/dental appointments						
Keeps a calendar of medical appointments						
Knows transportation to medical office						
Knows height, weight, birthdate, or carries information in wallet						
Knows how to use and read a thermometer						
Knows health emergency telephone numbers, or carries information in wallet						

Health Care Skills Checklist

Skill	Performs independently	Performs parts independently	Needs practice	Plan to start	Skill accomplished	Comments
Knows medical coverage numbers, or carries information in wallet						
Knows about medical insurance coverage						
Obtains sex education materials/birth control/ family planning information as needed						
Discusses role of general health maintenance						
Has considered genetic counseling if appropriate						
Knows about how drugs/alcohol affect illness/disability						
Makes contact with appropriate community advocacy organizations						
Takes care of own menstrual needs and keeps a record of monthly periods						
Has considered the need for a health advocate						
Has identified a physician for adult care						
Knows how to hire and manage a personal care attendant						

Health Care Skills Checklist

Skill	Performs independently	Performs parts independently	Needs practice	Plan to start	Skill accomplished	Comments

Adapted from "Adolescent Autonomy Questionnaire" in West, Margaret A., (Editor) (1988) *Assessment for Adolescents with Special Needs: A Guide for Transition Planning*. University of Washington Press, Seattle, Washington. PACER Center has received permission to use this material.

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Health Care Checklist for Residential Settings

Questions / Concerns	Responses
1. Do all the residents have the same doctor or go to the same clinic?	
2. Is it possible to keep our son or daughter's own physician/clinic?	
3. If we keep our own doctor, who is responsible for transporting our daughter or son to the clinic for routine care?	
4. Who is responsible for transporting our son or daughter for emergency care if we wish to use the hospital with which our physician is affiliated?	
5. What hospital is usually used for emergencies?	
6. Does the residence use specific consulting physicians who are specialists?	
7. Who takes a resident to doctor appointments? Is there a specific staff person assigned (e.g., nurse)?	
8. Who dispenses medications? Does this staff person have specialized training?	
9. Is there always someone staffing the residence during the daytime hours?	

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Health Care Checklist for Residential Settings

Questions / Concerns	Responses
10. What happens when someone becomes ill during the day?	
11. What are the communication guidelines set up to notify me about my son or daughter's visits to the clinic or about any illness?	
12. How often are residents asked to bathe or shower?	
13. Does the residence have a policy on sexuality?	
14. Are residents taught about sexuality?	
15. My son or daughter has these health concerns: (e.g., special diet, PT).	
16. I would like these specific guidelines in my daughter or son's record: (e.g., CPR staff)	
* How would these guidelines be carried through?	
* Who would perform these procedures?	
* Who would be training the staff who performs these procedures?	

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Are You Ready to Manage Your Own Health Care?

1.	I worry about my health.	Yes	No
2.	My parents always take care of all my health needs.	Yes	No
3.	I would like to know more about my illness/disability.	Yes	No
4.	I would like to be responsible for taking my own medications or doing my own treatments.	Yes	No
5.	It is easy for me to talk with my doctor.	Yes	No
6.	I feel I have little or no control over my illness/disability.	Yes	No
7.	I would like to speak with my doctor alone during visits.	Yes	No
8.	I would like to go to the doctor by myself.	Yes	No
9.	Sometimes I get embarrassed if I have to take my medications in front of my friends.	Yes	No
10.	If I follow my treatments and take my medications, my health is usually good.	Yes	No
11.	My health needs will affect my future.	Yes	No

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Personal Transition Health Plan: An Example

Personal Health Skills	What is the present skill level	Desired skill level	Personal strengths (which will help him/her learn skill)	Steps involved in this skill	Who is responsible (resources, persons who can help your child gain this skill)	Supports/Safety nets needed to assure success
Taking daily medication	Reminds parents to give medications Gets glass of water Swallows pills	Semi-independent * Consistently remembers to take medication * Takes pill from container	Tells time on digital watch Knows days of the week Ability to open containers	1. Fills daily pill holder 2. Knows correct time for pill 3. Knows why pill is taken 4. Knows serious side effects 5. Opens containers 6. Takes correct dosage 7. Knows when to get refill 8. Checks space on chart	Parents School nurse IEP Personal care attendant	Daily parental check of chart to record each dosage Assist child to get refill

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Personal Transition Health Plan: An Example

Personal Health Skills	What is the present skill level	Desired skill level	Personal strengths (which will help him/her learn skill)	Steps involved in this skill	Who is responsible (resources, persons who can help your child gain this skill)	Supports/Safety nets needed to assure success

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Responsibilities of a Health Advocate

- Organize information before a visit
- Keep appointments or cancel far in advance if possible
- Facilitate communication between patient and health care provider
- Share all relevant information with health care provider
- Clarify information and / or medication or treatment prescribed by provider
- Write down all information and directions
- Follow advice or report information accurately to caregivers

(Howard, 1990)

Sexuality, A Part of Health: Resources

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Kroll, K., and Klein, E.L. (1992) *Enabling romance: A guide to love, sex and relationships for the disabled (and the people who care about them)*. New York: Harmony Books.

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McKee, L., and Blacklidge, V. (1986) *An easy guide for caring parents -- Sexuality and socialization*. Walnut Creek, CA: Planned Parenthood and Oakland, CA: Association for Retarded Citizens.

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National Center for Youth with Disabilities (1992) *Issues in sexuality for adolescents with chronic illness and disabilities: A bibliography*. For information, call 1-800-333-6293.

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Westheimer, R. (1983) *Dr. Ruth's Guide to Good Sex*. New York, NY: Warner Books, Inc.

Planned Parenthood of Minnesota has a Resource Center that contains books and monographs, curriculum materials, and papers and articles. It also has educational brochures and audio-visual materials. Its address is 1965 Ford Parkway, St. Paul, MN 55116. Phone (612) 698-2401, or 1-800-832-6477 (in Minnesota).

States with High Risk Insurance Pools

Connecticut
Florida
Illinois
Indiana
Iowa
Maine
Minnesota
Montana
Nebraska
New Mexico
North Dakota
Oregon
Rhode Island
South Carolina
Tennessee
Washington
Wisconsin

Further information can be obtained from the insurance commissioners in each state.

List compiled May 1991

Offices of State Insurance Commissioners

Alabama Insurance Commissioner
135 South Union Street, Number 100
Montgomery, AL 36130-3351
(205) 269-3550

Alaska Insurance Commissioner
333 Willoughby
Juneau, AK 99801
(907) 465-2515

Arizona Insurance Commissioner
3030 North 3rd Street, Suite 1100
Phoenix, AZ 85012
(602) 255-5995

Arkansas Insurance Commissioner
400 University Tower Building
1123 South University Avenue
Little Rock, AK 72204
(501) 686-2945

California Insurance Commissioner
100 Van Ness Avenue
San Francisco, CA 94142
(415) 904-5410

Colorado Insurance Commissioner
1560 Broadway, Suite 850
Seventh Floor, West Tower
Denver, CO 80202
(303) 894-7499

Connecticut Insurance Commissioner
P.O. Box 816
Hartford, CT 06142-0816
(203) 297-3800

Delaware Insurance Commissioner
841 Silver Lake Boulevard
Dover, DE 19901
(302) 739-4251

District of Columbia Insurance Commissioner
613 G Street, NW
Sixth Floor, Suite 634
P.O. Box 37200
Washington, DC 20013
(202) 727-8000

Florida Insurance Commissioner
Department of Insurance
200 East Gaines Street
Tallahassee, FL 32399-0300
(904) 922-3132

Georgia Insurance Commissioner
2 Martin Luther King Jr. Drive
704 West Tower
Atlanta, GA 30334
(404) 656-2056

Hawaii Insurance Commissioner
250 South King St., Fifth Floor
Honolulu, HI 96813
(808) 586-2790

Idaho Insurance Commissioner
500 South 10th Street
Boise, ID 83720
(208) 334-4320

Illinois Insurance Commissioner
320 West Washington Street
Springfield, IL 62767
(217) 782-4515

Indiana Insurance Commissioner
311 West Washington Street
Suite 300
Indianapolis, IN 46204-2787
(317) 232-2385

Iowa Insurance Commissioner
Lucas State Office Building
Sixth Floor
Des Moines, IA 50319
(515) 281-5705

Kansas Insurance Commissioner
420 SW Ninth Street
Topeka, KS 66612-1678
(913) 296-3071

Kentucky Insurance Commissioner
P.O. Box 517
Frankfurt, KY 40602
(502) 564-6027

Louisiana Insurance Commissioner
950 North Fifth Street
Baton Rouge, LA 70802
(504) 342-5900

Maine Insurance Commissioner
State Office Building
State House, Station 34
Augusta, ME 04333
(207) 582-8707

Maryland Insurance Commissioner
501 St. Paul Place
Stanbalt Building, 7th Floor South
Baltimore, MD 21202
(410) 333-6300

Massachusetts Insurance Commissioner
100 Nashua Street
Boston, MA 02114
(617) 727-3750

Michigan Insurance Commissioner
611 West Ottawa Street
2nd Floor North
Lansing, MI 48933
(517) 373-0220

Minnesota Insurance Commissioner
133 East Seventh Street
St. Paul, MN 55101
(612) 296-2594
1-800-652-9747

Mississippi Insurance Commissioner
1804 Walter Sillers Building
P.O. Box 79
Jackson, MS 39201
(601) 359-3569

Missouri Insurance Commissioner
301 West High Street, Room 630
Jefferson City, MO 65102-0690
(314) 751-4126

Montana Insurance Commissioner
126 North Sanders
Mitchell Building, Room 270
Helena, MT 59620
(406) 444-2040

Nebraska Insurance Commissioner
Terminal Building
941 "O" Street, Suite 400
Lincoln, NE 68508
(402) 471-2201

Nevada Insurance Commissioner
1665 Hot Springs Road, Suite 152
Carson City, NV 89710
(702) 687-4270

New Hampshire Insurance Commissioner
169 Manchester Street
Concord, NH 03301
(603) 271-2261

New Jersey Insurance Commissioner
20 West State Street CN325
Trenton, NJ 08625
(609) 292-5360

New Mexico Insurance Commissioner
PERA Building
500 Old Santa Fe Trail, Fourth Floor
Santa Fe, NM 87501
(505) 827-4500

New York Insurance Commissioner
160 West Broadway
New York, NY 10013
(212) 602-0434

North Carolina Insurance Commissioner
Dobbs Building
430 Salisbury Street
Raleigh, NC 27611
(919) 733-7343

North Dakota Insurance Commissioner
Capitol Building, Fifth Floor
600 East Boulevard Avenue
Bismarck, ND 58505
(701) 224-2440

Ohio Insurance Commissioner
2100 Stella Court
Columbus, OH 43266-0566
(614) 644-2658

Oklahoma Insurance Commissioner
1901 North Walnut
Oklahoma City, OK 73105
(405) 521-2828

Oregon Insurance Commissioner
21 Labor and Industries Building
Salem, OR 97310
(503) 378-4636

Pennsylvania Insurance Commissioner
Strawberry Square, 13th Floor
Harrisburg, PA 17120
(717) 787-2317

Rhode Island Insurance Commissioner
233 Richmond Street, Suite 233
Providence, RI 02903-4233
(401) 277-2223

South Carolina Insurance Commissioner
1612 Marion Street
Columbia, SC 29201
(803) 737-6160

South Dakota Insurance Commissioner
Insurance Building
910 East Sioux Avenue
Pierre, SD 57501
(605) 773-3563

Tennessee Insurance Commissioner
Volunteer Plaza
500 James Robertson Parkway
Nashville, TN 37243
(615) 741-2176

Texas Insurance Commissioner
P.O. Box 149104
Austin, TX 78714-9104
(512) 463-6464

Utah Insurance Department
State Office Building
Room 3110
Salt Lake City, UT 84114
(801) 538-3800

Vermont Insurance Commissioner
89 Main Street, Drawer 20
Montpelier, VT 05620-3101
(802) 828-3301

Virginia Insurance Commissioner
700 Jefferson Building
1220 Bank Street
Richmond, VA 23219
(804) 786-3741

Washington Insurance Commissioner
Insurance Building
P.O. Box 40255
Olympia, WA 98504-0255
(206) 753-7300

West Virginia Insurance Commissioner
2019 Washington Street East
Charleston, WV 25305
(304) 558-3386

Wisconsin Insurance Commissioner
121 East Wilson Street
Madison, WI 53702
(608) 266-3585

Wyoming Insurance Commissioner
Herschler Building
122 West 25th Street
Cheyenne, WY 82002
(307) 777-7401

State Medicaid Agencies

Alabama Medicaid Agency
2500 Fairlane Drive
Montgomery, AL 36130
(205) 277-2710, extension 200

Alaska Medicaid Agency
Division of Medical Assistance
Department of Health and Social Services
P.O. Box 110660
Juneau, AK 99811-0660
(907) 465-3355

Arizona Medicaid Agency
Health Care Cost Containment System
801 East Jefferson
Phoenix, AZ 85034
(602) 234-3655, extension 4053

Arkansas Medicaid Agency
Office of Long Term Care
Department of Human Services
P.O. Box 1437, Slot 400
Little Rock, AR 72203-1437
(501) 682-8487

California Medicaid Agency
Medical Care Services
Department of Health Services
714 P Street, Room 1253
Sacramento, CA 95814
(916) 657-1496

Colorado Medicaid Agency
Bureau of Health and Medical Services
Department of Social Services
1575 Sherman Street, 10th Floor
Denver, CO 80203-1714
(303) 866-5901

Connecticut Medicaid Agency
Medical Care Administration
Department of Income Maintenance
110 Bartholomew Avenue
Hartford, CT 06106
(203) 566-2934

Delaware Medicaid Agency
Department of Health and Social Services
Delaware State Hospital
1901 North Dupont Highway
New Castle, DE 19720
(302) 577-4400

District of Columbia Medicaid Agency
Office of Health Care Financing
D.C. Department of Human Services
2100 Martin Luther King Jr. Ave. SE
Suite 302
Washington, DC 20025
(202) 727-0735

Florida Medicaid Agency
Health and Rehabilitation Services
1317 Winewood Boulevard
Building 6, Room 233
Tallahassee, FL 32399-0700
(904) 488-3560

Georgia Medicaid Agency
Department of Medical Assisitance
Floyd Veterans Memorial Building
West Tower - 1220C
2 Martin Luther King Jr. Drive SE
Atlanta, GA 30334
(404) 656-4479

Hawaii Medicaid Agency
Health Care Administration Division
Department of Human Services
P.O. Box 339
Honolulu, HI 96809-0339
(808) 586-5392

Idaho Medicaid Agency
Medicaid Policy and Reimbursement
Department of Health and Welfare
450 West State Street, Second Floor
Boise, ID 83720-5450
(208) 334-5795

Illinois Medicaid Agency
Medical Operations
Illinois Department of Public Aid
201 South Grand Avenue East
Springfield, IL 62763-0001
(217) 782-2570

Indiana Medicaid Agency
Medicaid Policy and Planning
Family & Social Services Administration
402 W. Washington St., Room W341
P.O. Box 7083
Indianapolis, IN 46207-7083
(317) 233-4448

Iowa Medicaid Agency
Division of Medical Services
Department of Human Services
Hoover State Office Building, Fifth Floor
Des Moines, IA 50319
(515) 281-8794

Kansas Medicaid Agency
Medical Services
Social and Rehabilitation Services
Docking Office Building, Room 628-S
915 Harrison Street
Topeka, KS 66612
(913) 296-3981

Kentucky Medicaid Agency
Department of Medicaid Services
Third Floor
275 East Main Street
Frankfort, KY 40621
(502) 564-4321

Louisiana Medicaid Agency
Bureau of Health Services Financing
P.O. Box 91030
Baton Rouge, LA 70804-9030
(504) 342-3891

Maine Medicaid Agency
Bureau of Medical Services
Department of Human Services
State House Station 11
Augusta, ME 04333
(207) 289-2674

Maryland Medicaid Agency
Health Care Policy, Finance & Regulation
Health and Mental Hygiene
201 West Preston Street, Fifth Floor
Baltimore, MD 21201
(301) 225-6535

Massachusetts Medicaid Agency
Department of Public Welfare
600 Washington Street
Boston, MA 02111
(617) 348-5691

Michigan Medicaid Agency
Medical Services Administration
Department of Social Services
P.O. Box 30037
Lansing, MI 48909
(517) 335-5001

Minnesota Medicaid Agency
Health Care Administration
Department of Human Services
442 Lafayette Road, Sixth Floor
St. Paul, MN 55155-3848
(612) 296-2766

Mississippi Medicaid Agency
Division of Medicaid
Office of the Governor
Robert E. Lee Building, Room 801
239 N. Lamar Street
Jackson, MS 39201-1399
(601) 359-6050

Missouri Medicaid Agency
Division of Medical Services
Department of Social Services
P.O. Box 6500
Jefferson City, MO 65102
(314) 751-6922

Montana Medicaid Agency
Medicaid Services Division
Social and Rehabilitation Services
P.O. Box 4210
Helena, MT 59604
(406) 444-4540

Nebraska Medicaid Agency
Medical Services Division
Department of Social Services
301 Centennial Mall South, Fifth Floor
Lincoln, NE 68509
(402) 471-9147

Nevada Medicaid Agency
Welfare Division
Department of Human Resources
2527 North Carson Street
Carson City, NV 89710
(702) 687-4378

New Hampshire Medicaid Agency
Office of Medical Services
Division of Human Services
6 Hazen Drive
Concord, NH 03301-6521
(603) 271-4314

New Jersey Medicaid Agency
Medical Assistance and Health Services
Department of Human Services
CN-712-7 Quakerbridge Plaza
Trenton, NJ 08625
(609) 588-2600

New Mexico Medicaid Agency
Medical Assistance Division
Human Services Department
P.O. Box 2348
Santa Fe, NM 87504-2348
(505) 827-4315

New York Medicaid Agency
Division of Medical Assistance
State Department of Social Services
40 North Pearl Street
Albany, NY 12243
(518) 474-9132

North Carolina Medicaid Agency
Division of Medical Assistance
Department of Human Resources
1985 Umstead Drive
P.O. Box 29529
Raleigh, NC 27626-0529
(919) 733-2060

North Dakota Medicaid Agency
Medicaid Operations
Department of Human Services
State Capitol Building, Judicial Wing
600 East Boulevard Avenue
Bismarck, ND 58505-0261
(701) 224-2321

Ohio Medicaid Agency
Medicaid Administration
Department of Human Services
30 East Broad Street, 31st Floor
Columbus, OH 43266-0423
(614) 644-0140

Oklahoma Medicaid Agency
Division of Medical Services
Department of Human Services
P.O. Box 25352
Oklahoma City, OK 73125
(405) 557-2539

Oregon Medicaid Agency
Office of Medical Assistance Programs
Department of Human Resources
203 Public Service Building
Salem, OR 97310
(503) 378-2263

Pennsylvania Medicaid Agency
Secretary of Medical Assistance
Department of Public Welfare
Health and Welfare Building
Room 515, Box 2675
Harrisburg, PA 17105-2675
(717) 787-1870

Rhode Island Medicaid Agency
Division of Medical Services
Department of Human Services
600 New London Avenue
Cranston, RI 02920
(401) 464-3575

South Carolina Medicaid Agency
Health and Human Services
Finance Commission
P.O. Box 8206
Columbia, SC 29202-8206
(803) 253-6100

South Dakota Medicaid Agency
Medical Services
Department of Social Services
700 Governors Drive
Kneip Building
Pierre, SD 57501-2291
(605) 773-3495

Tennessee Medicaid Agency
Bureau of Medicaid
729 Church Street
Nashville, TN 37247-6501
(615) 741-0213

Texas Medicaid Agency
Department of Human Services
P.O. Box 149030
Austin, TX 78714-9030
(512) 450-3050

Utah Medicaid Agency
Division of Health Care Financing
Utah Department of Health
P.O. Box 16580
Salt Lake City, UT 84116-0580
(801) 538-6478

Vermont Medicaid Agency
Division of Medicaid
Department of Social Welfare
Vermont Agency of Human Services
103 South Main Street
Waterbury, VT 05671-1102
(802) 241-2880

Virginia Medicaid Agency
Medical Assistance Services
600 East Broad Street
Suite 1300
Richmond, VA 23219
(804) 786-7933

Washington Medicaid Agency
Division of Medical Assistance
P.O. Box 45080
Olympia, WA 98504-5080
(206) 753-1777

West Virginia Medicaid Agency
Office of Medical Services
Bureau of Administration and Finance
Health and Human Resources
Building 6, State Capitol Complex
1900 Washington Street, East
Charleston, WV 25305
(304) 926-1700

Wisconsin Medicaid Agency
Bureau of Health Care Financing
Division of Health
Department of Health and Social Services
P.O. Box 309
Madison, WI 53701-0309
(608) 266-2522

Wyoming Medicaid Agency
Division of Health Care Financing
6101 Yellowstone Road
Cheyenne, WY 82002
(307) 777-7531

State Programs for Children with Special Health Needs

Alabama
Division of Rehabilitative and Crippled Children's Services
2129 East South Boulevard
Montgomery, AL 36111
(205) 281-8780

Alaska
Handicapped Children's Program
Department of Health & Social Services
1231 Gambell
Anchorage, AK 99501-4627
(907) 274-7626

Arizona
Office of Children's Rehab Services
Arizona Department of Health
1740 West Adams, Room 205
Phoeniz, AZ 85007
(602) 542-1860

Arkansas
Children's Medical Services
Department of Human Services
P.O. Box 1437
Little Rock, AR 72203
(501) 682-2277

California
California Children's Services
State Department of Health
714 F Street, Room 323
Sacramento, CA 94234-7320
(916) 322-2090

Colorado
Handicapped Children's Program
Colorado Department of Health
4210 East 11th Avenue
Denver, CO 80220
(303) 331-8404

Connecticut
Division of Children with Special Health Needs and Child/Adolescent Health
Bureau of Community Health
150 Washington Street
Hartford, CT 06106
(203) 566-2057

Delaware
Child Health/CSHN
Division of Public Health
P.O. Box 637
Dover, DE 19903
(302) 739-4735

District of Columbia
Bureau of Maternal & Child Health
Department of Human Services
1660 L Street, NW, Suite 904
Washington, DC 20036
(202) 673-6665

Florida
Children's Medical Services Program
Department of Health/Rehab Services
Building 5, Room 127
1323 Winewood Boulevard
Tallahassee, FL 32301
(904) 487-2690

Georgia
Children's Medical Services
Department of Human Resources
Division of Public Health
878 Peachtree Street NE, Suite 217
Atlanta, GA 30309
(404) 894-6622

Hawaii
Children with Special Health Care Needs
Hawaii Department of Health
741 Sunset Avenue
Honolulu, HI 96816
(808) 732-3197

Idaho
Children with Special Health Needs
Bureau of Maternal & Child Health
Department of Health/Welfare
450 West State Street
Boise, ID 83720
(208) 334-5963

Illinois
Division of Specialized Care for Children
University of Illinois at Chicago
2815 West Washington, Suite 300
P.O. Box 19481
Springfield, IL 62794-9481
(217) 793-2340

Indiana
Children's Special Health Care Services
Indiana State Board of Health
1330 W. Michigan Street
P.O. Box 1964
Indianapolis, IN 46204-1964
(317) 633-8522

Iowa
Iowa Child Health Specialty Clinic
University of Iowa
Iowa City, IA 52242
(319) 356-1118

Kansas
Children with Special Health Care Needs
Department of Health & Environment
900 SW Jackson, 10th Floor
Topeka, KS 66612-1290
(913) 296-1313

Kentucky
Commission for Handicapped Children
Department of Human Resources
1405 East Burnett Avenue
Louisville, KY 40217
(502) 588-3264

Louisiana
Handicapped Children's Services
Office of Public Health
Department of Health & Hospitals
P.O. Box 60630
New Orleans, LA 70160
(504) 568-5055

Maine
Coordinated Care Service for Children
with Special Health Needs
State House Station 11
151 Capitol Street
Augusta, ME 04333
(207) 289-3311

Maryland
Division of CCS
Department of Health/Mental Hygiene
Mental Retardation/D D Admin
201 W. Preston Street, 4th Floor
Baltimore, MD 21201
(301) 225-5580

Massachusetts
Bureau of Parent/Child/Adolescent Health
Department of Public Health
150 Tremont Street, 4th Floor
Boston, MA 02111
(617) 727-3372

Michigan
Children's Special Health Care Services
Bureau of Child and Family Services
Michigan Department of Health
P.O. 30195
Lansing, MI 48909
(517) 335-8964

Minnesota
Division of Maternal & Child Health
Minnesota Department of Health
717 Delaware Street SE
P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5166

Missouri
Maternal, Child & Family Health
Missouri Department of Health
1738 E. Elm Street
P.O. Box 570
Jefferson City, MO 65102
(314) 751-6174

Montana
Family and MCH Bureau
Health & Environmental Sciences
Cogswell Building
Helena, MT 59620
(406) 444-4740

Nebraska
Special Services for Children & Adults
Department of Social Services
301 Centennial Hall South, Fifth Floor
Lincoln, NE 68509-5026
(402) 471-9345

Nevada
MCH/CSHCS
Nevada State Health Division
505 East King Street, Room 205
Carson City, NV 89710
(702) 687-4885

New Hampshire
Bureau of Special Medical Services
Division of Public Health Services
6 Hazen Drive
Concord, NH 03301-6527
(603) 271-4596

New Jersey
Special Child Health Services Program
New Jersey Department of Health
CN 364
363 W. State Street
Trenton, NJ 08625-0364
(609) 292-5676

New Mexico
Children's Medical Services
Department of Health & Environment
P.O. Box 968
Santa Fe, NM 87504-0968
(505) 827-2350

New York
Bureau of Child/Adolescent Health
New York Department of Health
Corning Tower Building, Room 780
Empire State Plaza
Albany, NY 12237
(518) 474-2084

North Carolina
Child Health Branch
Environmental Health/Natural Resources
P.O. Box 2091
Raleigh, NC 27802-2091
(919) 733-7437

North Dakota
Crippled Children's Services
Department of Human Services
State Capitol Building, Judicial Wing
Bismarck, ND 58505
(701) 224-2436

Ohio
Division of Maternal & Child Health
Ohio Department of Health
246 North High Street
P.O. Box 118
Columbus, OH 43266-0118
(614) 466-3263

Oklahoma
Children's Medical Services Division
4545 N. Lincoln Blvd., Fourth Floor
Oklahoma City, OK 73103
(405) 557-2539

Palau
Ministry of Health Services
Republic of Palau
MacDonald Memorial Hospital
P.O. Box 100
Koror, Palau 96940

Oregon
Child Development/Rehabilitation Center
Oregon Health Sciences University
P.O. Box 574
Portland, OR 97207
(503) 494-8362

Pennsylvania
Division of Rehabilitative Services
Pennsylvania Department of Health
Room 714
P.O. Box 90
Harrisburg, PA 17108
(717) 783-5436

Puerto Rico
MCH & Children w/
Special Health Needs
Department of Health
Commonwealth of Puerto Rico
Call Box 70184
San Juan, PR 00936
(809) 767-0870

Rhode Island
Services for Handicapped Children
Rhode Island Department of Health
Three Capitol Hill
Providence, RI 02908-5098
(401) 277-2312

South Carolina
Division of Children's Health
Health & Environmental Control
2600 Bull Street
Columbia, SC 29201
(803) 737-4056

South Dakota
MCM/CSHS Programs
South Dakota Department of Health
118 W. Capitol
Pierre, SD 57501
(605) 773-3737

Tennessee
Children's Special Services
Department of Health/Environment
100 - 9th Avenue, North
Nashville, TN 37219-5405
(615) 741-7353

Texas
Bureau of Chronically Ill
& Disabled Children Services
Texas Department of Health
1100 West 49th Street
Austin, TX 78756-3179
(512) 458-7355

Utah
Children's Special Health Services Bureau
Utah Department of Health
Cannon Building
288 North 1460 West
Salt Lake City, UT 84116-0650
(801) 538-6957

Vermont
Handicapped Children's Services
Vermont Department of Health
1193 North Avenue
P.O. Box 70
Burlington, VT 05401
(802) 863-7338

Virginia
Children's Specialty Services
Virginia Department of Health
109 Governor Street
Richmond, VA 23219
(804) 786-3691

Washington
Children with Special Health Needs
Division of Parent Child Health Services
Department of Health
Mailstop LC-11A
Olympia, WA 98504
(206) 753-0908

West Virginia
Division of Handicapped Children
Department of Health/Human Services
1116 Quarrier Street
Charleston, WV 25301
(304) 348-6330

Wisconsin
Wisconsin Division of Health
P.O. Box 309
Madison, WI 53701
(608) 266-3674

Wyoming
Children's Health Services
Division of Health and Medical Services
Wyoming Department of Health
Hathaway Building
Cheyenne, WY 82002-0710
(307) 777-7941

Paying for Health Care: Resources

Beckett, J. (1989) *Health care financing: A guide for families.* Iowa City, IA: National Maternal and Child Health Resource Center, College of Law Building, the University of Iowa, Iowa City, IA 52242; (319) 335-9067.

Larson, G., and Kohn, J. (1990) *Special needs, special solutions -- How to make health care systems work for your child with special needs: Services and ways to pay for them.* St. Paul, MN: Pathfinders Resources, Inc., 2324 University Avenue West, Suite 105, St. Paul, MN 55114; (612) 647-6905.

McManus, P. (1988) *Understanding your health insurance options -- A guide for families who have children with special health care needs.* Washington, DC: Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814; (301) 654-6549.

National Resource Centers

National Information Center for Children and Youth with Disabilities
P.O. Box 1492
Washington, DC 20013-1492
800-999-5599
703-893-6061 (DC area only)
703-893-8614 (TDD)

A clearinghouse for information and resources on children and youth with disabilities.

National Center for Youth with Disabilities
University of Minnesota
420 Delaware Street SE
Box 721
Minneapolis, MN 55455
800-333-6293
612-626-2825 (MN only)
612-624-3939 (TDD)

An information and resource center to improve services for youth with disabilities. Services include newsletter, annotated bibliographies for professionals, families and young people.

HEATH
One Dupont Circle
Suite 800
Washington, DC 20036
800-544-3284

The HEATH Resource Center is a clearinghouse that operates under a Congressional mandate to collect and disseminate information nationally about disability issues in post-secondary education.

National Council for Independent Living
2111 Wilson Boulevard
Suite 405
Burlington, VA 22201
703-525-3406

Parent Training and Information Centers

Parent Training and Information Centers are federally funded organizations in each state that provide training on a variety of issues to parents of children and youth with disabilities.

Alabama
Carol Blades, Director
Special Education Action Committee
P.O. Box 161274
3207 International Drive, Suite C
Mobile, AL 36606-3037
(205) 478-1208 Voice and TDD
FAX: (205) 473-7877

Alaska
Judie Ebbert-Rich
Alaska P.A.R.E.N.T.S. Resource Center
P.O. Box 32198
Juneau, AK 99803
(907) 790-2246 (TDD is available)
FAX: (907) 790-2248

Arizona
Mary Slaughter / Judy Walker
Pilot Parent Partnerships
2150 E. Highland Ave., No. 105
Phoenix, AZ 85016
(602) 468-3001

Arkansas
Bonnie Johnson
Arkansas Disability Coalition
10002 W. Markham, Suite B7
Little Rock, AR 72205
(501) 221-1330 Voice and TDD

Arkansas
Barbara Semrau
FOCUS, Inc.
2917 King St., Suite C
Jonesboro, AR 72401
(501) 935-2750
(501) 221-1330 Voice and TDD

California
Diane Lipton/Pam Steneberg
DREDF
2212 Sixth Street
Berkeley, CA 94710
(510) 644-2555

California
Joan Kilburn/Audray Holm
Matrix, Parent Network
& Resource Center
P.O. Box 6541
San Rafael, CA 94903
(415) 499-3877

California
Florene Poyadue/Olivia Hernandez
Parents Helping Parents
535 Race St., Suite 140
San Jose, CA 95126
(408) 288-5010

California
Joan Tellefsen
Team of Advocates for
Special Kids (TASK)
100 West Cerritos Ave.
Anaheim, CA 92805-6546
(714) 533-8275
FAX: (714) 533-2533

Colorado
Barbara Buswell / Judy Martz
PEAK Parent Center, Inc.
6055 Lehman Drive, Suite 101
Colorado Springs, CO 80918
(719) 531-9400
(719) 531-9403 TDD
FAX: (719) 531-9452

Connecticut
Nancy Prescott
CT Parent Advocacy Center, Inc. (CPAC)
5 Church Lane, Suite 4
P.O. Box 579
East Lyme, CT 06333
(203) 739-3089 (TDD)

Delaware
Marie-Anne Aghazadian
Parent Information Center (PIC)
700 Barksdale Road, Suite 6
Newark, DE 19711
(302) 366-0152
(302) 366-0178 (TDD)

District of Columbia
Charlene Howard
COPE
P.O. Box 90498
Washington, DC 20090-0498
(202) 526-6814

Florida
Janet Jacoby
Family Network on Disabilities
5510 Gray Street, Suite 220
Tampa, FL 33609
(813) 289-1122
FAX: (813) 286-8614

Georgia
Patricia Smith
Parents Educating Parents (PEP)
1851 Ram Runway, Suite 104
College Park, GA 30337
(404) 761-2745
FAX: (404) 767-2258

Hawaii
Kathy Gould / Susan Klopotek
AWARE
200 N. Vineyard Blvd., Suite 310
Honolulu, HI 96817
(808) 536-2280 (Voice & TDD)
FAX: (808) 543-2222

Idaho
Debra Johnson
Idaho Parents Unlimited, Inc.
4696 Overland Road, Suite 478
Boise, ID 83705
(208) 342-5884
FAX: (208) 342-1408

Illinois
Charlotte Des Jardins
Family Resource Center on Disabilities
20 E. Jackson Blvd., Room 900
Chicago, IL 60604
(312) 939-3513

Illinois
Donald Moore
Designs for Change
220 S. State St., Suite 1900
Chicago, IL 60604
(312) 922-0317
FAX: (312) 922-6993

Indiana
Richard Burden
IN*SOURCE
833 Northside Blvd., Bldg. 1, Rear
South Bend, IN 46617
(219) 234-7101
FAX: (219) 287-9651

Iowa
Carla Lawson
Iowa Pilot Parents
Iowa Exceptional Parent Center
33 North 12th Street
P.O. Box 1151
Fort Dodge, IA 50501
(515) 576-5870
FAX: (515) 576-8209

Kansas
Patricia Gerdel
Families Together, Inc.
1023 Southwest Gage Street
Topeka, KS 66604
(913) 273-6343

Kentucky
Paulette Logsdon
KY-SPIN
2210 Goldsmith Lane, Suite 118
Louisville, KY 40218
(502) 456-0923

Louisiana
Debbie Braud
Project PROMPT
4323 Division Street, Suite 110
Metairie, LA 70002-3179
(504) 888-9111

Maine
Janice LaChance / Margaret Squires
Special Needs Parents Info Network
P.O. Box 2067
Augusta, ME 04338-2067
(207) 582-2504
1-800-325-0220 (TDD, Maine only)

Maryland
Cory Moore and Larry Larsen
Parents Place of Maryland, Inc.
7257 Parkway Drive, Suite 210
Hanover, MD 21076
(410) 712-0900 (Voice and TDD)
FAX: (410) 712-0902

Massachusetts
Artie Higgins
Federation for Children w/ Special Needs
95 Berkeley St., Suite 104
Boston, MA 02116
(617) 482-2915 (Voice and TTY)
FAX: (617) 695-2939

Michigan
Sue Pratt
CAUSE
313 S. Washington Square, Suite 040
Lansing, MI 48933
(517) 485-4084
FAX: (517) 485-4145

Michigan
Martha Wilson, Project Coordinator
Parents are Experts
23077 Greenfield Road, Suite 205
Southfield, MI 48075-3744
(313) 557-5070 Voice / TDD / TDY
FAX: (313) 557-4456

Minnesota
Marge Goldberg
Paula F. Goldberg
PACER Center, Inc.
4826 Chicago Avenue S.
Minneapolis, MN 55417
(612) 827-2966 Voice & TDD
FAX: (612) 827-3065

Mississippi
Ginger Smith
Association of Developmental
Organizations of Mississippi (ADOM)
332 New Market Drive
Jackson, MS 39209
(601) 922-3210
FAX: (601) 922-6854

Missouri
Marianne Toombs
Missouri Parents Act
1722W S. Glenstone, Suite 125
Springfield, MO 65804
(417) 882-7434 (TDD)
FAX: (417) 882-8413

St. Louis Office
625 North Euclid, Suite 405
St. Louis, MO 63108
(314) 361-1660 (Voice & TDD)
FAX: (314) 361-4087

Kansas City Office
1115 East 65th Street
Kansas City, MO 64131
(816) 333-6833 or 333-2323
FAX: (816) 333-3225

Montana
Katharin Kelker
Parents Let's Unite for Kids
1500 North 30th St., Room 267
Billings, MT 59101-0298
(406) 657-2055
FAX: (406) 657-2061

Nebraska
Jean Sigler
NE Parents' Info & Training Center
3610 Dodge St.
Omaha, NE 68131
(402) 346-0525

Nevada
Charlene Rogerson
Parent Connection
Nevada Technology Center
2860 E. Flamingo, Suite I
Las Vegas, NV 89121-2922
(702) 735-2922 (Voice & TDD)

New Hampshire
Judith Raskin
Parent Information Center
P.O. Box 1422
Concord, NH 03302-1422
(603) 224-7005 (Voice & TDD)
FAX: (603) 224-4365

New Jersey
Diana Cuthbertson
Statewide Parent Advocacy Network
516 North Ave. East
Westfield, NJ 07090
(908) 654-7726 Voice & TDD

New Mexico
Rosemary Silversmith
EPICS Project
P.O. Box 788
Bernalillo, NM 87004
(505) 867-3396
FAX: (505) 867-3398
(Call first to dedicate line)

New Mexico
Linda Coleman / Duane Edwards
Parents Reaching Out
1127 University Blvd. NE
Albuquerque, NM 87102
(505) 842-9045
FAX: (505) 842-1451

New York
Joan Watkins
Parent Network Center
1443 Main Street
Buffalo, NY 14209
(716) 885-1004

New York
Diana Autin
Advocates for Children of NY
24-16 Bridge Plaza S.
Long Island City, NY 11101
(718) 729-8866 (TDD)
FAX: (718) 729-8931

New York
Karen Schisinger
Resources for Children w/ Special Needs
200 Park Avenue S., Suite 816
New York, NY 10003
(212) 677-4650
FAX: (212) 254-4070

North Carolina
Connie Hawkins
ECAC, Inc.
P.O. Box 16
Davidson, NC 28036
(704) 892-1321
FAX: (704) 892-6149
(Call first to dedicate line)

North Carolina
Brenda Patton
Families First Coalition, Inc.
300 Enola Road
Morgantown, NC 28655
(704) 433-2662
FAX: (704) 438-6457

North Dakota
Kathryn Erickson
Pathfinder Parent Center
Arrowhead Shopping Center
16th St. and 2nd Ave. SW
Minot, ND 58701
(701) 852-9426
FAX: (701) 838-9324

Ohio
Cathy Heizman
Child Advocacy Center
1821 Summit Road, Ste. 303
Cincinnati, OH 45237
(513) 821-2400 (TTY)
FAX: (513) 821-2442

Ohio
Margaret Burley
OCEHC
1299 Campbell Road, Suite B
Marion, OH 43302
(614) 382-5452 Voice & TDD
FAX: (614) 382-2399

Oklahoma
Sharon Bishop
Parents Reaching Out in OK
1917 S. Harvard Avenue
Oklahoma City, OK 73128
(405) 681-9710
FAX: (405) 685-4006

Oregon
Cheron Mayhall
Oregon COPE Project
999 Locust St. NE, Box B
Salem, OR 97303
(503) 373-7477 (Voice & TDD)

Palau
Philomina Milong
Palau Parent Network
P.O. Box 1583
Koror, Republic of Palau 76740
(608) 488-3513
FAX: 01-1680 488-2830

Pennsylvania
Gail Walker
Mentor Parent Program
Route 257, Salina Road
P.O. Box 718
Seneca, PA 16346
(814) 676-8615

Pennsylvania
Christine Davis
Parents Union for Public Schools
311 S. Juniper St., Suite 602
Philadelphia, PA 19107
(215) 546-1166

Pennsylvania
Louise Thieme
Parent Education Network
333 East Seventh Avenue
York, PA 17402
(717) 845-9722 Voice & TDD
FAX: (717) 848-3654

Puerto Rico
Carmen Selles Vila
Parents Training Parents by ANPI
P.O. Box 21301
San Juan, PR 00928-1301
(809) 765-0345 (Telephone and FAX)
(809) 763-4665

Rhode Island
Peter Gillis
Rhode Island Parent Information Network
500 Prospect Street
Pawtucket, RI 02860
(401) 727-4144

South Carolina
Colleen Lee
PRO-PARENTS
2712 Middleburg Drive, Suite 102
Columbia, SC 29204
(803) 779-3859

South Dakota
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